

**A NARRATIVE APPROACH: BARRIERS AND FACILITATORS TO ACCESS AND
CARE IN SERVICES FOR YOUTH EATING DISORDERS IN ATLANTIC CANADA**

by

© Michael Bartellas, B.Sc. (Hons)

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ABSTRACT

Through a narrative approach, this thesis explores youth and family perspectives on experiences in accessing eating disorder services in Atlantic Canada. These narrative journeys were explored through conversations with a range of participants (five youth and six parents) in a one to one interview setting, thus providing rich and specific experiential data. The main barriers discovered were a lack of psychological services, guidance from family physicians, resources, and eating disorder education. Main facilitators included having a knowledgeable family physician, psychological support, an outpatient program, an eating disorder advocacy organization, and an adolescent eating disorder service. Major recommendations focus on increasing the number of experienced clinical psychologists in the province and increasing specific eating disorder training for service providers. This type of multi-vocal data is novel in Atlantic Canada, and holds value in including voices of youth and their families when exploring how to better improve services. The findings are interpreted in relation to ecological models of youth development.

Keywords: Eating Disorders, Barriers, Facilitators, Access, Care, Youth, Atlantic Canada, Narrative Inquiry, Patient Journeys

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List of Abbreviations

Academy for Eating Disorders [AED]

ACCESS Mental Health Project [ACCESS-MH]

American Psychiatric Association [APA]

Anorexia Nervosa [AN]

Avoidant/Restrictive Food Intake Disorder [ARFID]

Body Mass Index [BMI]

Bulimia Nervosa [BN]

Cognitive-behavioural therapy [CBT]

Canadian Institutes of Health Research [CIHR]

Canadian Mental Health Association [CMHA]

Diagnostic and Statistical Manual of Mental Disorders-5th edition [DSM-5]

Eating Attitudes Test [EAT-26]

Eating Disorders Interprofessional Community Capacity Building Team [EDICCB]

Employee Assistance Program [EAP]

Interpersonal therapy [IPT]

Mental Health Commission of Canada [MHCC]

National Initiative for Eating Disorders [NIED]

Public Health Agency of Canada [PHAC]

World Health Organization Statistical Information System [WHOSIS]

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Chapter 1: Introduction

The initial section of this chapter provides a background for the larger research project, followed by a context for the present study. The purpose and significance of the study is described, followed by a discussion of the thesis scope and important definitions. The final section is a brief overview of the remaining thesis chapters.

1.1. Background

In Canada, an estimated 1.2 million youth are affected by mental health challenges, with less than 20% of these individuals receiving the care they require (Mental Health Commission of Canada (MHCC), 2013). Across the country, over the last ten years between 15- 25% of the child/youth population has suffered from a mental health problem/illness (Kirby, 2008). Why is it that nearly one million Canadian youth with a mental illness do not receive adequate help?

There are many reasons why these individuals do not receive the treatment they need. For instance, a barrier such as stigma is highly related to mental illness, and this may prevent many individuals from seeking help (Corrigan, Druss, & Perlick, 2014; Leavey, Vallianatou, Johnson-Sabine, Rae, & Gunpath, 2011). In some cases, specialized care is not available in specific regions or provinces, or there may be practical difficulties such as waiting lists or a failure of previous treatment attempts which prevent individuals from accessing treatments now (Leavey et al., 2011). In other cases, it may take some time before a proper diagnosis is received, and there may be several delays to the start of treatment after this diagnosis (Wang, Berglund, Olfson, & Kessler, 2004). Parental attitudes towards their child's mental health may act as a barrier to initial care if the youth relies on their parent to get them into treatment (Janicke, Finney, & Riley, 2001; Wang et al., 2004). In certain scenarios, there may be higher levels of dysfunction for individuals who are experiencing a mental health disorder. This dysfunction could create delays

in treatment, such as an individual taking a long time to reach out and establish initial contact with a health care professional for treatment (Wang et al., 2004).

Identification of youth who have a mental illness was one priority recognized by the Mental Health Commission of Canada (MHCC, 2012). The Commission noted that earlier identification leads to prompt diagnosis and thus more timely intervention. This could help individuals who have a mental illness be better prepared to manage their daily living.

Throughout Canada there is a lack of a coordinated system for youth mental health care (Kirby, 2008). Appropriate treatment for children with mental health disorders often involves a plethora of services and multiple providers across sectors including health professionals, educators, and social workers (Canadian Institute of Health Research (CIHR), 2013). Individuals may have to manage and coordinate their own care among, and within various sectors. Due to this lack of coordination, there are often long wait times, system inefficiencies, and poor outcomes (CIHR, 2013).

Atlantic Canada Children's Effective Service Strategies in Mental Health (ACCESS-MH) is a CIHR-funded project exploring the barriers and facilitators in the child and youth mental health system in Atlantic Canada. The following excerpt provides a succinct project synopsis:

Our team of researchers across Atlantic Canada is currently working to deepen understanding of child/youth mental health in the region. The *Atlantic Canada Children's Effective Service Strategies in Mental Health* project (ACCESS-MH; <http://access-mentalhealth.ca/>) is a 5-year initiative funded by the Canadian Institutes of Health Research. It employs the newest knowledge on youth journeys and arts-based methods and melds it with the analysis of provincial and national statistical data (e.g., provincial

administrative data and statistics, Statistics Canada, Health Canada, CIHI, NLSCY). The combination of quantitative and qualitative methods provides an opportunity to examine mental health conditions and the mental health system from a variety of perspectives. While analysis of statistical data allows for exploration of systemic patterns, the inclusion of journeys and voices of children and youth allows for deeper understandings of the patient perspective as they navigate the system. A voiced journeys approach is especially suited to understanding the complex contexts of young lives. The ACCESS-MH patient journeys study engages all partners in the mental health system in leading conversations with parents, youth, teachers, primary health care providers, and community members. Led by a team of five researchers who bring diverse experiences and expertise in health economics, operations research, clinical psychology, research by/for/with youth, and qualitative research methods, it is also informed by an Advisory Committee with representation from multiple sectors and across the four Atlantic Provinces. (Tilleczek, Bell, & Lezeu, 2014, p. 10).

As a part of this larger CIHR mental health initiative, my thesis project specifically focused on the experiences of adolescents/young adults and their families who have been affected by eating disorders in one Atlantic Canadian province. My guiding research question is: ***What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?*** Using a narrative approach, I have explored participant journeys in the health system, and identified barriers and facilitators in the current provincial care setup. In addition, through interpretation of these participant narratives, I have developed several recommendations to improve access and care for eating disorder services. The aim of this project is to better understand what is working in the current system and what is not, and the findings will be shared

to help inform policy makers and practitioners about how to better meet the health care needs of youth and their families affected by eating disorders. From a theoretical standpoint, there is also much to learn from a study of this nature, since this type of research is novel in the Atlantic Canadian, Canadian, and even North American eating disorder field.

The present study is embedded in exploring the patient and family experience of navigating the system as they struggle with an eating disorder. Furthermore, this study investigates how youth and their families accessed and experienced these services. These specialized eating disorder services in the province included an eating disorder outpatient program, an adolescent eating disorder service, care in a pediatric psychiatric unit, and care in an internal medicine unit. Through this research, suggestions about how current services might be improved and what new services can be recommended have been formulated.

1.2. Context

According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) (DSM-5) (APA, 2013), eating disorders are characterized as a constant eating or eating behaviour disorder leading to a distorted consumption of food, which has a significant impact on both physical and/or psychosocial aspects.

Eating disorders have a huge negative impact on quality of life, affecting psychological and physical aspects of health (Jenkins, Hoste, Meyer, & Blissett, 2011). Individuals with eating disorders have reported a lower quality of life compared to the general population, “relating to emotional reactions, social isolation, and home relationships” (Jenkins et al., 201, p 115). In addition to a reduced quality of life, anorexia nervosa (a type of eating disorder) has the highest mortality rate of all psychiatric conditions, with 10% of individuals dieing as a result of this disorder (Sullivan, 2002). This is especially disconcerting because less than 20% of individuals

with an eating disorder will be treated by a mental health professional (Mond, 2007). This information has been a driving force for the need to further explore the barriers, which might explain why 80% of individuals who have an eating disorder do not receive specialized care.

The following section provides a context for understanding eating disorders, and the current provincial eating disorder context. Eating disorders are complex mental illnesses. There are major psychological and physical issues associated with these disorders, which mainly present through an abnormal perception of body image and eating habits. According to the DSM-5 (APA, 2013), feeding and eating disorders can be classified into eight categories; anorexia nervosa, bulimia nervosa, binge-eating disorder, other specified feeding or eating disorders, pica, rumination disorder, avoidant/restrictive food intake disorder (ARFID), and unspecified feeding or eating disorder. Associated with these disorders are high rates of comorbidity with other psychiatric disorders, in particular anxiety, depression, bipolar, and obsessive-compulsive disorders (APA, 2013).

Eating disorders are ten times more likely to affect females than males (World Health Organization (WHO), 2004), with the most common population being female youth, where eating disorders are the third most common chronic illness. Nationally, 3% of women and 0.3% of men are affected by an eating disorder within their lifetime (Canadian Mental Health Association (CMHA), 2013). According to Statistics Canada (2002), there are 424,767 individuals at risk of having an eating disorder in Canada, with 31,987 of these individuals being in Atlantic Canada. This information was obtained from a self-reported study of individuals within these areas who were below an eating disorder symptomology threshold when exploring their responses. The only information the provincial health data repository was able to relay for more present day findings was that 0.2% of individuals 15 and older have self-reported to having

an eating disorder in Atlantic Canada (Statistics Canada, 2013). This data was derived from a nationwide voluntary self-reported survey. There is currently little data on prevalence rates of eating disorders in each Atlantic Canadian province, however the *Canadian Community Health Survey: Mental health and well-being* (2002) report stated that the province being studied has reported eating disorder prevalence rates that are equal to the largest Canadian provinces and are amongst the highest in the country (Statistics Canada, 2002). This latest statistic published in the province regarding prevalence of eating disorders dates back more than a decade. This prompts the need to gain more current and relevant eating disorder information for each Atlantic Canadian province. There are a variety of different eating disorders, however only individuals who have a self-reported diagnosis of anorexia nervosa or bulimia nervosa are included in the current study. This inclusion criterion is derived from the ACCESS-MH project. Below is a description of the provincial context of eating disorder services.

1.2.1. Provincial Youth Eating Disorder Services.

Compared to a decade ago, there is a much-improved level of service available for individuals who have eating disorders in the province. There are also support options available for families, which were not available ten years ago. Treatment options vary drastically across the variety of provincial health authorities districts. The current inpatient option for children who are medically unstable within the capital city is the children's hospital; where there are seven acute care psychiatry beds, with two specifically for children with eating disorders.

In a separate health region, there is an outpatient counselling service provided to youth and their families surrounding mental illness. They can also provide outpatient eating disorder service, and this community-based program was created in 1996. The inpatient option for eating disorder care in this health region is in a women and children's health unit that has four beds

allotted for adolescent mental health. It is important to note that there are no specialized eating disorder services across the province except for in the capital city. Additionally, more than a third of child hospital admissions related to anorexia nervosa in the province occurred outside of the capital city, which was noted in a report for government on the need for an intensive day treatment program, with data derived from the provincial health data repository (Heath, 2004). This shows that eating disorder prevalence is not limited to the urban population but is a province wide issue, affecting those in rural areas as well. Recently, there has been advancement in eating disorder services and support in the province. However, there is a long way to go in order to identify and provide adequate support and access for the thousands of individuals in the province who have not availed of any specific eating disorder care.

1.2.1.1. Adolescent Eating Disorder Service.

In the province there is an adolescent eating disorder service that operates out of an outpatient clinic in a large urban area. This specialized eating disorder care is offered from a multidisciplinary team of health professionals trained in the care of adolescent health. This team also consults with professionals in the inpatient children's psychiatric unit and with referrals at the outpatient program. This provincial adolescent eating disorder service assessed 68 new patients in 2011, where 18 of these patients were diagnosed with an eating disorder as their primary illness (Faculty of Medicine- Adolescent Medicine, 2011). Throughout that year, a total of 22 patients were admitted to hospital for management of their eating disorder. Looking back to the 2001-2003 period, there were 33 eating disorder admissions for children within the capital city (Heath, 2004).

1.2.1.2. Provincial Outpatient Program.

A provincial eating disorder outpatient day treatment program has an intake age of 15 years and older, which operates out of a large urban area. The individual must also be medically stable to enter this program. The program is designed for individuals diagnosed with anorexia nervosa, bulimia nervosa or an otherwise specified eating disorder. The centre offers meal supports, music therapy, psychotherapy, art therapy, relapse prevention, and several other programs. The program also helps to facilitate support for caregivers and family members of those affected with an eating disorder, in affiliation with a local advocacy organization. In 2012, the outpatient centre had 79 referrals, 42 clients accepted into the program and 18 clients graduate from the program (Program Administrator, October 23, 2013). The percentages of clients with anorexia nervosa, bulimia nervosa and otherwise specified eating disorder were 36%, 31%, and 33% respectively.

1.2.1.3. Local Eating Disorder Advocacy Organization.

There is a single eating disorder advocacy group in the province. This group aims to promote research, provide information about eating disorders, and provide support for individuals who have an eating disorder, along with their families. They also promote public education and awareness surrounding eating disorders, such as through the *Let's Talk Eating Disorders Program*, which provides information sessions to educators, and schools all across the province. The advocacy organization offers a variety of other programs and services, some of the major ones include: an eating disorder educational program, family and sibling support groups, resource loans, research grants, and a scholarship program.

1.2.1.4. The Interprofessional Eating Disorder Working Group.

This working group, created by health care professionals, had an objective to focus their efforts on working with individuals who had eating disorders. The eating disorder interprofessional group developed and implemented an eating disorder education program for professionals across the province with the objective of improving care for individuals and families affected by eating disorders. This initiative was summarized in a 2012 report to Government. This report highlights the positive outcomes of the initiative, such as participants feeling more knowledgeable and aware about eating disorders, and more confident in dealing with eating disorders.

1.3. Significance

In the Atlantic Canadian province under evaluation in this thesis, there are approximately 7,400 individuals at risk of having an eating disorder (Statistics Canada, 2002). Eating disorders are serious health conditions that may lead to death if left untreated. Anorexia nervosa has the highest mortality rate of any mental illness, with approximately 10% of these individuals dying within 10 years of onset (Sullivan, 2002). Looking at global mortality rates, the United States has the highest rate at 218 deaths per year representing 36% of global deaths from an eating disorder (World Health Organization Statistical Information System (WHOSIS), 2003). Canada has the fifth highest mortality rate from eating disorders, at 19 deaths per year, which is 3.1% of global eating disorder deaths (WHOSIS, 2003). Data regarding deaths caused by specific eating disorders was last reported nationally in 2009, with eight deaths due to anorexia nervosa, eight from other eating disorders and one from bulimia nervosa (Statistics Canada, 2013).

There is little research in the eating disorder services field in Atlantic Canada and even less exploration of barriers and facilitators to access and care. Within the province under study, there

has been a research exchange group developed which provides a space where provincial eating disorder research can be shared. However, besides this group, it has been difficult to collect eating disorder research in the context of this specific Atlantic Canadian population. This being said, there was one study that explored the experiences and treatment needs of women who had eating disorders, from both patient and provider perspectives in the province. This study provides many similar findings with the current study, and is crucial for comparison of advancements in care (Heath, Beausoleil, & Ryan, 2006).

1.4. Purpose

The purpose of this study is to explore barriers and facilitators in youth and family eating disorder journeys in both a) access and b) care in the health care system in one Atlantic Canadian province. Barriers and facilitators to youth access and care in eating disorder services have been examined and identified. The data has been collected from the perspectives of youth and parents, to obtain a multi-voice image of these experiences.

The guiding research question is: ***What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?*** This study has been guided by various recent research findings (Boydell et al., 2006; Heath, et al., 2006; Tilleczek & Lezeu, 2014; Tilleczek, Ferguson, Campbell & Lezeu, 2014). Additionally, other questions that have helped guide the research process are derived from the larger ACCESS-Mental Health (ACCESS-MH) Project (Tilleczek et al., 2014), including: ***What health services are these patient populations currently accessing? What services are they accessing through other agencies (e.g., education, social work, private sector providers)? and What services are effective/ineffective and why?***

1.5. Scope Of Thesis

The narrative journey interviews have been collected from two different participant groups. These include youth participants who have accessed the provincial health care system with a self-reported diagnosis of anorexia nervosa or bulimia nervosa and parents of youth who reported a diagnosis of an eating disorder. Of the 11 participants interviewed, three were dyads (six people) from the same family.

It is important to note that the findings from this study are not generalizable since qualitative research makes no such claim. They are connected to the experiences of a certain group of individuals operating in the context of the publically administered health care system in Atlantic Canada. The nature of qualitative inquiry is to develop interpretations and theories that are relevant to the participants studied. The data from this study reflect the experiences of individuals who were willing to participate in the study and who were recruited through the various organizations. The views of these participants are not entirely representative of all individuals who have accessed youth eating disorder services in the province. However, they provide rich and nuanced accounts of the ways in which barriers and facilitators are encountered and negotiated.

1.6. Thesis Outline

This thesis is divided into five chapters, references and Appendices. The Appendices provide supporting data and documentation for the thesis. The second chapter is a comprehensive review of the literature. The review showed that there is little research exploring access and care in Atlantic Canadian eating disorder services, especially from a multi-perspective qualitative approach. There was also little research exploring barriers and facilitators to accessing eating disorder services generally, and even less in the context of a youth population alone.

Recommended evidence-based treatment modalities were explored in the context of national guidelines and the literature for youth who had anorexia nervosa or bulimia nervosa. The third chapter provides the method and methodology employed for the study. Chapter four reports the study findings. The findings reveal several recurring themes in participant facilitator and barriers to mental health, and eating disorder access and care. Some of these findings were paradoxical and circumstance dependent. However, the major themes were related to lack of specific health care providers, eating disorder knowledge on the part of service providers, access to resources such as desired appropriate food, and admission to the hospital or an outpatient program. The final chapter is a discussion of the findings and recommendations for the future. These recommendations, like the findings, are multilayered and complex. They are positioned in context of the Complex Cultural Nesting theory, which is detailed in the following pages.

Chapter 2: Literature Review

2.1. Scope of Literature Review

The focus of this chapter is to explore the qualitative eating disorder research, and more specifically the barriers and facilitators to accessing care, however other types of research were utilized when appropriate as well. PubMed and Google Scholar were used to explore the qualitative eating disorder literature. Through filtering for articles within the past 10 years and for the 0 to 18 year old population there were 100 articles found. However, after manual screening, there were four articles that appropriately explored participant experiences in accessing eating disorder care. These qualitative articles varied in their specific topic of exploration in regards to eating disorders. The inclusion criteria for this search were variations of the terms *eating disorder*, and *qualitative research*. A similar search was conducted when exploring the barriers and facilitators to mental health care, and eating disorder care using PubMed and Google Scholar, filtering for articles within the past 10 years, and for the 0 to 18 year old population. The inclusion criteria for mental health care barriers and facilitators were variations of the terms *barriers*, *facilitators*, *access*, and *mental health*, and for the eating disorder barriers and facilitators were variations of the terms *barriers*, *facilitators*, *access*, and *eating disorders*. Through a similar process of manual screening two articles were appropriate for mental health care, and zero for eating disorders. The search was refined for the eating disorder barriers and facilitators by removing the 0-18 filter, and removing the search term *facilitators*, which then produced 1 viable article. Additionally, several appropriate articles were discovered through reviewing the study references. Also, another qualitative piece of research was provided, which explored barriers to eating disorder care in the Atlantic Canadian context (Heath et al., 2006).

There was a variation in the location of the studies with only one being positioned in Atlantic Canada, a few being located in Canada, and the majority of the articles coming from international sources. When available, studies using a strict adolescent sample were utilized, however many of the studies used a mixed adult/adolescent sample or a pure adult sample. When exploring the barriers and facilitators to treatment for mental health, and eating disorder services qualitative studies were mainly utilized, with some mixed methods studies as well.

The type of eating disorder is not necessarily specified in each of the studies in this literature review. However, there are two major subtypes of eating disorders of interest in this thesis, which will be briefly reviewed below.

2.2. Anorexia Nervosa

The general prevalence rate for anorexia nervosa across Canada has been proposed to range between 0.3% to 3.7 % (Langlois, Samokhvalov, Rehm, Spence, & Gorber, 2012; Public Health Agency of Canada (PHAC), 2006). Through a Canadian pediatric surveillance survey, it was observed that early-onset of restrictive eating disorders in the 5-12 years of age population was 2.6 per 100,000, with prevalence in girls six times more than boys (Pinhas, Morris, Crosby, & Katzman, 2011). There were approximately 46% of these Canadian children aged 13 years or younger who were under the 10th percentile for body mass index, and 62.1% of these children met anorexia nervosa diagnostic criteria (Pinhas et al., 2011). It is important to note that this study predates the inclusion of ARFID as a diagnostic category (DSM-5, 2013). The authors did mention that a part of their study population would have fallen into this category instead of early-onset anorexia nervosa if ARFID had been a classification at that time, which may be a reason these rates were highly reported. The 10-12 year old group had the highest incidence rate, with girls showing 9.4 cases per 100,000 and boys showing 1.3 cases per 100,000 (Pinhas et al.,

2011). Another report from southern Ontario observed that 27% of girls in the 12-18 year old cohort reported significant symptoms of eating disorders, through analysis of their Eating Attitudes Test (EAT-26) scores (Jones, Bennett, Olmsted, Lawson, & Rodin, 2001).

There are three criteria required for a diagnosis of anorexia nervosa (DSM-5, 2013). The first is a restriction of energy intake, which leads to a significantly low body weight in context of the individual. The next criterion is an intense fear of gaining weight, becoming “fat” and/or behaviour that interferes with weight gain, although the individual is already significantly underweight. The last requirement is the undue influence of weight and shape on self-image, and/or a constant lack of recognition of the seriousness of their current low body weight (DSM-5, 2013). An adolescent medicine specialist would be the most likely health care provider to make this diagnosis in Atlantic Canada, however other clinicians may also make this diagnosis.

The American Psychiatric Association’s practice guidelines (APA, 2006) and the *Guideline Watch (August 2012): Practice guideline for the treatment of patients with eating disorders* (Yager et al., 2012) are appropriate sources to explore the recommended treatment options for eating disorders. For anorexia nervosa, the recommended treatment options involve nutritional rehabilitation (Garber, Michihata, Hetnal, Shafer, & Moscicki, 2012; Lock, 2010; Pike, Walsh, Vitousek, Wilson, & Bauer, 2003; Rigaud, Brayer, Roblot, Brindisi, & Vergès, 2011), psychosocial interventions such as cognitive-behavioural therapy (CBT) or interpersonal therapy (IPT) (Byford et al., 2007; Dare, Eisler, Russell, Treasure, & Dodge, 2001; Gowers et al., 2007; Lampard & Sharbanee, 2015; Pike et al., 2014), family therapy (Dare et al., 2001; Eisler, Simic, Russell, & Dare, 2007; Eisler, Dare, Hodes, Russell, Dodge, & Le Grange, 2000; Geist, Heinmaa, Stephens, Davis, & Katzman, 2000; Le Grange, et al., 2012; Le Grange, Crosby, Rathouz, & Leventhal, 2007; Lock et al., 2010; Lock, Agras, Bryson, & Kraemer, 2005; Robin,

Siegel, & Moye, 1995; Robin, Siegel, Koepke, Moye, & Tice, 1994), and some types of pharmacotherapy (Aigner, Treasure, Kaye, & Kasper, 2011). Family therapy is the most supported treatment option for this population (Yager et al., 2012).

A further description of a few of the participant discussed treatment options include: family-based therapy, cognitive-behavioural therapy (CBT) and interpersonal therapy (IPT). Family-based therapy is an intervention observed to be most effective for youth under the age of 19 (Yager et al., 2012), where the family is used as a resource for the youth who has an eating disorder (Eisler et al., 2000; Lock et al., 2005). CBT identifies cognitions an individual has related to certain stimuli (Schmidt, 2009). These cognitions can result in dysfunctional emotions or maladaptive behaviours. The primary goal of IPT is to help patients identify and modify interpersonal problems that may be a factor in their disordered eating (Weissman, Markowitz, & Klerman, 2008).

2.3. Bulimia Nervosa

The general prevalence rate for bulimia nervosa across Canada has been proposed to range between 1.1% to 4.7 % (PHAC, 2006). The global prevalence rates for bulimia nervosa from the APA practice guidelines (2006) are 1% to 4.2% for women. Researchers used the DSM-III-R threshold criteria to screen for the possibility of developing bulimia nervosa in a study exploring bulimia nervosa prevalence in a nonclinical community sample in Ontario (Garfinkel et al., 1995). From this Canadian study the reported rates for developing bulimia nervosa were 1.1% for women and 0.1% for men.

There are five criteria required for an individual to be diagnosed with bulimia nervosa (APA, 2013). The first is recurrent episodes of binge-eating, which involves eating an excessive amount of food in a set period of time and a sense of lack of control during this episode. This

must occur once a week for three months. The next criterion is recurrent inappropriate compensatory behaviours, such as self-induced vomiting, misuse of laxatives, diuretics, fasting, or excessive exercise. This must also occur once a week for three months. Additionally, the individual must have an undue influence of shape and weight on their self-image. Lastly, in order to be classified with bulimia nervosa, these disturbances must occur outside of an episode of anorexia nervosa. Similarly to anorexia nervosa, an adolescent medicine specialist would be the most likely health care provider to make this diagnosis, with other clinicians, such as psychiatrists also able to make this diagnosis.

For bulimia nervosa, the recommended treatment options (APA, 2006; Yager et al., 2012) include psychosocial interventions, such as CBT and IPT (Fairburn, Jones, Peveler, Hope, & O'Connor, 1993; Fairburn et al., 1991; Fairburn, Cooper, & Shafran, 2003; Hay, Bacaltchuk, Stefano, & Kashyap, 2009; Lock, 2005), self-help programs (Perkins, Murphy, Schmidt, & Williams, 2006; Traviss, Heywood-Everett, & Hill, 2011), group psychotherapy (APA, 2006), family therapy (Le Grange et al., 2007; Schmidt et al., 2007), pharmacotherapy (Aigner et al., 2011), and a combination of psychotherapy and pharmacotherapy (Bacaltchuk, Hay, & Trefiglio, 2002; Bruce, Pen, & Koran, 1992; Goldbloom et al., 1997; Mitchell et al., 2011; Walsh et al., 1997). The recommended treatment option for bulimia nervosa is a CBT approach (Yager et al., 2012).

2.4. Treatment Pathways and Setting for Youth With Eating Disorders

In regards to treatment pathways, there are three main options: inpatient treatment (including residential), day treatment or outpatient services (APA, 2006). There is extensive variability for outpatient treatment through clinics and specialized outpatient programs. An important point to note is that when transitioning from one treatment setting to another there

must be a continuity of care as this transition process can be destabilizing for patients (APA, 2006). The use of similar service providers in the new setting, and a care coordinator can help in this transition process.

2.4.1. Inpatient Treatment.

In extreme cases of illness, particularly when an individual is medically unstable, inpatient treatment or hospitalization is required (APA, 2006; Wallier et al., 2009). The primary reason for hospitalization is for medical stabilization, with a focus on refeeding and bed rest (Academy for Eating Disorders (AED), 2012). Medical stability is evaluated on a variety of items such as a history, physical examination, laboratory testing, and an electrocardiogram. For youth and adolescents, there is also a developmental, educational, and cognitive assessment on top of an assessment for medical, and psychological factors (AED, 2012). An after care plan must be made once a patient is medically stable, and the medical staff deem it safe to discharge the patient. This plan typically involves follow-up appointments, and can involve a transition into day treatment or an outpatient program.

2.4.1.1. *Residential Eating Disorder Programs.*

A subset of inpatient services is a residential eating disorder program. Patients in this setting live in a facility for seven days a week, and are required to stick to a predetermined schedule of daily activities and therapies (Frisch, Herzog, & Franko, 2006). The main difference between treatment in an inpatient setting versus a residential setting is that there is more of a focus on the patient's medical stability in the inpatient setting (Yager et al., 2012). The residential treatment program would be the next level of care required if an individual was not improving in outpatient day treatment. This intervention requires a patient to be medically stable. A comprehensive review of residential treatment programs, revealed the average length of stay to

be 83 days (Frisch et al., 2006). These programs offer several different therapies including various group and individual therapies (Frisch et al., 2006).

2.4.2. Outpatient Day Treatment.

An outpatient day program is a treatment option for individuals who are medically stable but require further help to recover. These day programs, according to Green et al. (2015), offer an intermediary option between inpatient and outpatient treatment, offering both nutritional and psychological support. Most day programs offer daily intensive care, however the participant returns home each day and keeps their social connections (Goldstein et al., 2011; Weaver, Sit, & Liebman, 2012). This allows for a regularly monitored test of patient progression, while managing stressors in their home environment (Abbate-Daga et al., 2009). The frequency with which an individual may use a day treatment program differs across organizations, with some offering treatment three or four days per week and others offering treatment five or seven days per week (Abbate-Daga et al., 2009). Most of the successful day programs involve treatment five days a week and for eight hours on each of those days (Olmsted, Kaplan, & Rockert, 2003). When considering if a patient can take the step down to day treatment, there must be an examination of the patient's motivation for treatment, and how they will function in a group environment (Garner & Garfinkel, 1997; Kaye, Kaplan, & Zucker, 1996).

Day treatment programs differ in types of services offered. Some examples of services provided include pharmacological therapy, psychodynamic groups, body image therapy, music therapy, art therapy, CBT, and meal support (Abbate-Daga et al., 2009). These day programs provide support from psychologists, physicians, nurses, social workers, and dieticians. In these programs, there is often support from other individuals who have an eating disorder as well (Abbate-Daga et al., 2009). According to the day program review from Abbate-Daga et al.

(2009), the major goals of day treatment programs are the modification and normalisation of eating behaviour through nutritional rehabilitation, weight gain, and identification and resolution of processes that perpetuate the eating disorder.

2.4.3. Choice of Treatment Settings.

As there is much variation across the essential features of settings, it is difficult to discern a clear conclusion on the benefits of a specific setting as a treatment option for individuals (Yager et al., 2012). In analyzing the interventions at the inpatient, residential, and day program settings, Lock (2010) was not convinced that hospitalization had advantages over the other programs. There is little data on the differences between these distinctive treatment settings, but it has been suggested that hospitalization can create unnecessary family separation, and anxiety for the adolescent (Lock, 2010). It has also been proposed that inpatient treatment does not provide major advantages over outpatient management for anorexia nervosa treatment (Gowers et al., 2007). Similarly, in a national British study, there was little support for long-term inpatient care in terms of participant preference, or clinical, or financial reasons when compared to other specialized services available (Gowers et al., 2010). An opposing view comes from a study in Norway that suggests that adolescents having anorexia nervosa may display positive outcomes upon 3-14 year follow ups after completing time in a structured inpatient or partial hospitalization treatment (Halvorsen, Andersen, & Heyerdahl, 2004).

In looking at treatment settings for anorexia nervosa, it was noted that there may be a more rapid weight gain through an inpatient setting than an outpatient setting (Yager et al., 2012), but other measures of recovery were comparable in both settings (Hartmann, Weber, Herpertz, & Zeeck, 2011). In regards to bulimia nervosa, the guidelines recommend outpatient treatment,

except in circumstances where the individual needs to be hospitalized such as during episodes of suicidality, or psychosis (Yager et al., 2012).

2.5. Qualitative Literature on Eating Disorder Treatment

In addition to quantitative studies, qualitative techniques are recognized as important tools for eating disorder research (Bezance & Holliday, 2013). As mentioned previously, the present study utilizes in-depth qualitative interviews. This style of narrative interviewing gives vulnerable participants an opportunity to voice their perspective and express their personal experiences (Minichiello, Aroni, Timewell, & Alexander, 1995). It is important to take a brief look at the qualitative literature on patient experiences with eating disorder treatment. This process will help to provide a context for previous work in this field, which can guide how we interpret the current thesis findings. This section has been organized into a variety of themes related to the study findings.

The most useful article discovered was a review of qualitative studies in adolescent experiences with treatment and recovery for their anorexia nervosa (Bezance & Holliday, 2013). In this review, it was proposed that qualitative research in the adult population largely focuses on the experience of having anorexia nervosa (e.g. Malson, 1999; Skårderud, 2007). In the adolescent anorexia nervosa population, Bezance and Holliday cited (Boughtwood & Halse, 2010; Colton & Pistrang, 2004; Tierney, 2008) in noting that there is a focus on qualitative research in the areas of treatment and recovery, using a variety of differing qualitative methodologies. Colton & Pistrang (2004), Halse et al., (2005) and Van Ommen, Meerwijk, Kars, Van Elburg, & Van Meijel, (2009) cited in Bezance & Holliday, (2013) explore the experience of treatment, where the setting is typically concentrated on inpatient care. Through analysis of these adolescent qualitative studies a variety of themes were identified such as the role of the

family, peers, health professionals, the inpatient setting, the physical and psychological aspects of treatment and recovery, and how recovery is conceptualized (Bezance & Holliday, 2013).

These themes will be discussed below with reference to their original sources when available.

In exploring these themes in more detail, the role of the family focused on the sibling influence in the experience of having anorexia nervosa (Honey, Clarke, Halse, Kohn, & Madden, 2006). The findings indicated that siblings can have both a negative or positive influence, with three proposed specific mechanisms on how siblings influence their sibling who has an eating disorder, such as; presence/existence, response to anorexia, and indirect influence. Siblings at times felt that they contributed to the development of their sibling's eating disorder or acted as a trigger toward their sibling. The sibling at times also rejected their sibling after hearing they had an eating disorder, and in other cases the relationship was unchanged or the sibling offered support, which provided some relief.

Bezance and Holliday (2013) note that the role of peers was another theme highlighted in many of the studies reviewed (e.g. Colton & Pistrang, 2004; Offord, Turner, & Cooper, 2006; Turrell, Davis, Graham, & Weiss, 2005; Van Ommen et al., 2009), with an emphasis on peer connections made while in treatment in an inpatient setting. Some studies suggested that these peer friendships promoted recovery, and positive attitudes (Colton & Pistrang, 2004; Offord et al., 2006; Van Ommen et al., 2009), where others described these friendships as facilitating negative behaviours, spurring competition, and producing increased distress (Boughtwood & Halse, 2010; Colton & Pistrang, 2004; Offord et al., 2006).

Another theme was in the role that the health professional had in regards to care and accessing specialized eating disorder services. This access was problematic at times because family physicians had not recognized symptoms of eating disorders in their participants (Tierney,

2008). The adolescents mentioned that once in treatment, there were issues with insensitive comments from the providers that were a cause for distress (Tierney, 2008). Many of the youth participants also felt that their health providers were dishonest by nature (Boughtwood & Halse, 2010). It was suggested that experienced providers, along with a team specialising in eating disorder care was valuable, and the ideal provider would be sensitive to the participant, empathetic, consistent, and clear with their dialogue (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009).

There was also a theme exploring perception of the inpatient setting. One study mentioned that the inpatient setting helped with structure and encouraged adolescents to take on responsibilities for their own recovery (Van Ommen et al., 2009). Another study (Offord et al., 2006) opposed this view, claiming the inpatient setting was detrimental for youth development, because it removed adolescents from regular society. The inpatient setting thus created difficulties at patient discharge for the youth transitioning back into normal living. Another study (Turrell et al., 2005) explored the discharge readiness of patients from inpatient care. There was recognition of several factors that enabled youth to feel ready for their discharge, such as medical stability, education, psychological changes, and community resource planning. An inpatient study (Halse et al., 2005) explored participant experience with being fed through a nasogastric feeding tube. Themes that emerged from this research included nasogastric feeding being an unpleasant physical experience, being a necessary or helpful intervention, and being a physical and psychological signifier of anorexia.

Another topic explored was the difference between physical and psychological aspects of treatment and recovery. In one example participants felt there was a focus more on the physical recovery rather than the psychological recovery in standardized treatment programs (Offord et

al., 2006). There was also recognition that the most beneficial treatments explored emotions associated with weight gain, in addition to psychological and physical recovery (Offord et al., 2006).

Bezance and Holiday (2013) recognized that eating disorder recovery was perceived differently when analyzing a variety of different studies (Colton & Pistrang, 2004; Tierney, 2008). Without the motivation to truly recover, participants felt their weight would come back off after hospital discharge (Colton & Pistrang, 2004; Tierney, 2008). Anorexia was mentioned to be helpful and detrimental by participants, and that their eating disorder played a constant dual role between good and bad (Colton & Pistrang, 2004).

The next two articles explore the theme of parental perspectives. The first study focuses on parents' recognition in their child having an eating disorder and in their pathway to seeking help (Thomson et al., 2014). In this study, parents often misinterpreted early signs of anorexia nervosa with normal adolescent development, and when they started to become suspicious they turned to the Internet for support. Therefore it was recommended that parents received early advice and support to confirm their suspicions, and also to improve awareness of credible websites that may help reduce delays in help seeking. The second study explored the experiences caregivers had when caring for someone who had anorexia nervosa (Whitney et al., 2005). This study highlighted caregivers as perceiving anorexia nervosa to be "chronic and disabling", and placing the blame on themselves contributing to the illness. The parents perceived themselves to be helpless in promoting their child's recovery, with the mothers showing intense emotional responses, and the fathers displaying a more detached account. The study recommendations focused on training parents to develop the necessary skills to manage their child's illness.

The next theme explores the use of multi-perspectives in qualitative eating disorder literature. Kyriacou, Easter, and Tchanturia (2009) explored youth, parent and clinician perspectives on the emotions of individuals who had anorexia nervosa. The researchers recognized that obtaining the perspectives of these three different groups would hold value to truly understanding their research objective. The study's specific objective was to explore what patients, parents, and clinicians pinpoint as the main issues regarding emotions and social cognition in anorexia nervosa. The participants included six current inpatient youth (mean age of 26.8 years) who had anorexia nervosa, 12 parents (mean age 52.6 years) who were currently caring for a person having anorexia nervosa, and clinicians. The clinicians included nurses (N = 7), psychiatrists (N = 3), and psychologists (N = 9) who worked in an eating disorder unit. The data was collected from a series of focus groups, and through an equivalent email questionnaire made available for those who could not make the focus group. Throughout the exploration of the responses there were many points of similarities and few points of differences across the participant groups. There were a total of seven themes recognized in the study, and all participant groups were in agreement regarding six of these themes. These themes included: emotional awareness and understanding, inability to cope with and tolerate emotions, emotional avoidance, expressions of emotions and negative beliefs, extreme emotional responses, social interactions and interpersonal relationships, and lack of empathy. However, lack of empathy was the single theme where patients and parents disagreed. A final note by Kyriacou et al. (2009) was that multi-perspectives produce a complex, multifaceted, and interrelated profile of problems. All of these viewpoints and themes hold value for the current thesis as it has incorporated multi-vocal experiences, and has further explored how these perceptions influence our understanding of the findings. Along with this study, the study by Heath et al. (2006) also explored multi-perspectives

in eating disorder care. This study is explored fully in the section below, titled Barriers and Facilitators to Eating Disorder Services.

2.6. Barriers And Facilitators To Accessing Mental Health Treatment

There was little qualitative research found regarding the barriers and facilitators to accessing treatment for eating disorders. There was more literature when looking at barriers and facilitators to care for mental health as a whole. Through exploring this literature, there was discovery of barriers at the personal, systemic, and environmental level (Boydell et al., 2006), as well as financial and administrative barriers (Sarvet, 2009). Only one article found provided a major exploration of facilitators to care in one of the articles (Boydell et al., 2006). There was also one systematic review exploring the perceived barriers and facilitators to mental health help seeking in youth (Gulliver, Griffiths, & Christensen, 2010).

Help seeking is a major consideration in exploring the subject of access. In 2010, Gulliver, Griffiths, and Christensen published a systematic review in which they explored adolescent perceived barriers and facilitators to mental health care help seeking. Several barriers and one facilitator were recognised through a thematic analysis of the 22 published studies in adolescent mental health experience. The unique findings from the review article will be directly referenced from Gulliver et al. (2010), however primary sources have been used when exploring the specific articles in more detail.

The first barrier explored was the presence of self-stigmatising attitudes, and embarrassment about seeking help. Gulliver et al. (2010) cites several studies (e.g. Aisbett, Boyd, Francis, Boyd et al., 2007; Francis, Boyd, Aisbett, Newnham, & Newnham, 2006; 2007) that mention stigma as prominent barrier, and even more so in a rural location.

A separate barrier discovered was in participants not being able to identify their symptoms as those of a mental illness (e.g. Biddle, Donovan, Sharp, & Gunnell, 2007; Rickwood, Deane, & Wilson, 2007). Participants instead perceived these symptoms as being normal and thus would avoid seeking help. Another major barrier was a lack of accessibility to services, specifically in rural areas. It was reported that individuals who had a mental disorder had increased barriers to locating available help when compared to those who did not have a mental disorder in a rural sample (Fox, Blank, Rovnyak, & Barnett, 2001). A barrier that youth mentioned was in wanting to be self-reliant, and deal with their own issues, instead of seeking support from others (Rickwood et al., 2007). There were also concerns about certain characteristics of service providers that deterred participants from seeking their help, such as if they were known by the participant, or their perceived ability to provide help (Helms, 2003; Lindsey & Kalafat, 1998).

Several participants lacked knowledge about mental health services, which acted as a barrier (Rickwood et al., 2007; Rickwood, Deane, Wilson, & Ciarrochi, 2005). Barker, Olukoya, and Aggleton (2005) discuss the connection between personal and structural determinants of health and how these factors influenced their participants' knowledge of health services, along with their ability to access health support. These participants for example did not view their family doctor as being an appropriate person to help them. Connected to this was an anxiety and fear about the process of seeking help. This acted as a barrier for participants, however when participants already had an established relationship with their provider this proved to be encouraging.

Several articles (Lindsey et al., 2006; Timlin-Scalera, Ponterotto, Blumberg & Jackson, 2003; Wilson & Deane, 2001) discussed that a positive past experience with care acted as a

facilitator to future help-seeking behaviours. This positive experience provided participants with confidence to reach out for help if needed.

Boydell et al. (2006) were able to explore perceived access to mental health services in the context of rural Canada. The study involved conducting interviews and focus groups with parents who had children that were formally diagnosed with an emotional and/or behavioural disorder. When looking at the previous articles reviewed, several of the findings were comparable-and some differed-which will be explored more throughout this discussion. The study (Boydell et al., 2006) findings highlighted barriers and facilitators in three categories: personal, systemic, and environmental. The personal category included experiences at the individual level, such as from youth or family perspectives; the systemic category included factors related to health care services; and the environmental category included considerations in the context of the rural community, such as geographical and population size.

In terms of the personal barriers: stigma, lack of information, and financial difficulties were highlighted. In relation to stigma, family members wanted to avoid having their child be “labelled”, and made visits to their providers at night to avoid seeing others. This was consistent with findings in other studies (Aisbett, et al., 2007; Boyd et al., 2007; Francis et al., 2006). Additionally, participants generally mentioned there was a lack of awareness of what mental health services were available, which has also be noted in other studies (Barker et al., 2005; Rickwood et al., 2005; 2007). The third barrier in this category was financial difficulties, which is especially important in the rural context, as families would have to travel significant distances to access services, incurring out of pocket costs, and taking time off work. The two personal facilitators were word of mouth, and advocacy, which were both observed as unique findings in the current study when compared to the other literature reviewed. The word of mouth facilitator

entailed informal support from others in the community in supporting access to mental health care. Parents said that advocacy was a big facilitator in that families had increased access when they were being a “squeaky wheel.” The opposite of this was true as well, in that parents who did not push hard enough often did not receive the services their child needed. This was a unique finding when compared to the aforementioned studies.

Systemic barriers voiced were: human resources, policy and funding issues, waiting time, and invisibility (Boydell et al., 2006). There was a shortage of human resources mentioned by several participants, including a lack of specialized services and specialists, which is also found in the literature (Boydell et al., 2006). Appointments were often “brief encounters” due to the limited number of providers, which was frustrating for families, as they felt undervalued. Related to this lack of resources was an increase in waiting period for appointments, found in other works (Leavey et al., 2011). Parents mentioned that it was normal to have to wait a few months for an appointment, where others had to wait a year or two. Although, participants did mention there was availability of care in times of acute need. In regards to policy and funding issues, a key point was that government policies often ensured strict intake criteria that made accessing services difficult, such as patient age at admission. The last barrier addressed through Boydell et al.’s study (2006) was the invisibility of having a mental illness. This was a finding found in the current study but not elsewhere in the literature reviewed. Parents found an increased difficulty in accessing services for their child’s mental health issue as the illness was not tangible, which led to an increased need for a formal diagnosis. There were two facilitators recognized at the systemic level: delivery of personalized services, and offering services in local communities. Personalized service focused on the characteristics of many of the rural service providers, who were often described as being “good people” and “open minded.” There was a willingness of

these providers to travel to participants, to provide transportation, and a variety of other measures of accommodation, which increased family engagement in the treatment process. These provider characteristics such as a willingness to accommodate, and being empathetic and open minded are also echoed in other literature (Helms, 2003; Lindsey & Kalafat, 1998). Connected with this facilitator were the benefits of offering services locally. Through positioning services in these rural communities many of the participant barriers are diminished. A major idea in offering services locally was that children could stay connected to their families and communities, which is less disruptive for the child and their family, and this increases the likelihood of a continuation in treatment.

The single environmental barrier was the distance families had to travel to access out-of-town services; for example, this could include issues related to adverse weather conditions (Boydell et al., 2006). This is different from the previous barrier mentioned, where the previous barrier explored more of the financial burdens associated with travel, such as money lost from taking time off of work. This barrier was echoed in other work as well (Fox et al., 2001). The single environmental facilitator was in the benefits of living in a small community, which meant having longstanding relationships with community members and service providers. This helped in that service providers would at times drive to a patients home to deliver care, or take a youth out to lunch for counselling.

In the article by Sarvet (2009) the focus was on a number of barriers that obstruct American primary care clinicians' delivery of mental health services to youth and their families. It is important to note that this study was positioned in the United States, where the health care system is different from the Canadian system, thus presenting differing barriers and facilitators. The focus of these barriers was on the lack of appropriate payment for the range of mental health

services provided by primary care clinicians, such as in consultations with parents alone or other care providers, and a lack of financial incentive to create a multidisciplinary mental health treatment team (Sarvet, 2009). There was also mention of inadequate communication and co-management amongst physicians and various mental health and school professionals. Another theme reported related to financial and administrative barriers that limited access to effective psychosocial interventions (Sarvet, 2009). In Canada there is a fee for service set up for primary care providers where similar barriers to interprofessional care may exist, as providers have no financial compensation for meeting with other professionals.

There have been several barriers and some facilitators reported through reviewing this literature on accessing mental health services. These studies have explored this topic from a variety of perspectives. The major barriers to help seeking revealed in this literature review include stigma (Aisbett et al., 2007; Boyd et al., 2007; Boydell et al., 2006; Francis, et al., 2006), lack of knowledge of available services (Barker et al., 2005; Boydell et al., 2006; Rickwood et al., 2005; 2007), and a lack of recognition in one's mental health symptomology. The major facilitators discovered were in having a positive past experience with services (Lindsey et al., 2006; Rickwood et al., 2005; Timlin-Scalera et al., 2003), having an experienced provider and team (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009), and having a provider who was empathetic and sensitive to the patient (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009). There was more of a focus on the barriers in these studies than on the facilitators to accessing care. Many of the barriers were revealed in a diversity of the studies, and it will be important to examine if similar barriers are voiced in the current thesis. It is also important to note that the setting of many of the studies were outside of Canada and this may be something that influences whether similar themes are discovered in the current thesis as well.

2.6.1. Barriers and Facilitators To Accessing Eating Disorder Treatment.

This section describes studies that are from the patient perspective, and are specific to barriers and facilitators to accessing eating disorder care.

Leavey et al. (2011) examined the psychosocial barriers to engagement with an eating disorder service in the United Kingdom. In order to locate participants, the researchers used an audit of patients who dropped out of treatment with an eating disorder clinic. Out of the 22 randomly selected participants 13 agreed to be interviewed, with 11 of these participants never attending the clinic for their initial appointment, and two participants having attended for only the initial assessment. The findings from these interviews revealed two main themes. The first theme identified was the practical difficulties that were associated with eating disorder services. These included wait times, previous bad experiences, and dissonance between the provider and the patient. The second major theme was social-psychological barriers. There were several subthemes within the psychosocial barriers, such as; early childhood trauma, fear of abandonment, depression and anxiety, loss of control, loss of coping mechanism, social and emotional avoidance, and ambivalence toward treatment (Leavey et al., 2011). This is of interest because few studies have included participants who have dropped out of treatments.

The following report was published as a poster, which was a part of a study named *Development of an Intensive Outpatient Treatment Program for Eating Disorders: a Cost-Benefit Analysis* (Heath et al., 2006). It is important to note this study occurred in one Atlantic Canadian province. The basis of the report was an analysis exploring the experiences and treatment needs in the province from two focus groups: women who had eating disorders, and health professionals (Heath et al., 2006). The participants ages ranged from 16 to 53, meaning that some of the participants accessed services at the pediatric hospital, while other accessed

services in the adult psychiatric unit. The provider/treatment accessed by participants in this report, from highest to lowest frequency, were: psychologist, support group, psychiatrist, dietician, outpatient services, medication, social worker, marriage counsellor, and art therapist. Out of the 12 patient participants, two had never been institutionalized for treatment, nine had been hospitalized, and four had attended an out of province residential treatment centre. The treatment setting of the participants is important to note because the experiences of these participants are focused on a specific treatment or service setting. There were several themes discovered in this report, I will discuss the relevant ones for the current thesis.

The first category of themes was experiences in the context of inpatient treatment (Heath et al., 2006). The first theme in this category was the facilitator of health care workers who were patient and provided genuine caring. One example of this comes from a participant who said “we’d have a lot of the same nurses often and some of them were really great and really fun to talk to and they’d ... like just by talking to you, they’d be distracting you from feeling so crappy a lot of times.” The next theme was that the hospital experience was overall quite negative. Participants felt that they lost their dignity and independence in the hospital, with one participant stating “I remember saying to my psychiatrist – I will die before I go back in there. Like I cannot put myself through like another four months of that. It is not going to happen.” The following theme was that a majority of the staff were poorly trained in eating disorder treatment, leading to destructive outcomes in patient care. As one participant articulated, “I don’t think they’re (the staff) specifically trained even though they are in the Psych. Unit and probably shouldn’t be.” The last theme in this inpatient category was that staff seemed to approach treatment with a uni-dimensional focus, such as gaining weight, but ignored the underlying issues of the eating disorder. With participants echoing that they may physically “recover” in hospital but are not

emotionally prepared when they are discharged. One participant summarized this theme by saying “It is a mental illness (but) all that’s dealt with is physically.”

In the next category of themes participants spoke towards general treatment, and that there was a general lack of availability of treatment options with one participant mentioning it took them six months to access a psychiatrist, which they felt was too long (Heath et al., 2006). The final main finding in this study was related to what participants perceived as an ideal treatment. The first suggestion was in implementing a multidisciplinary approach to treatment, in which all providers were communicating with each other. The next suggestion was implementing some sort of transition program for patients, thus allowing for easier transition back into the community from their hospital discharge. Another suggestion was to provide more support and resources to families, as they were usually quite involved with treatment. One participant alluded to creating a support group for families and relatives to learn more about eating disorders. The final suggestion was to include the voices of peers in the treatment process. Peers in this sense would include other individuals who have had an eating disorder and who could truly understand how patients felt and could offer advice on how to successfully recover from having an eating disorder.

Evans et al. (2011) focused on a longitudinal Australian sample of women who had been identified with clinically severe eating disorder symptomology. The study objective was to explore the barriers to help-seeking in a community sample of women who had bulimic type of eating disorders: bulimia nervosa (N=7), binge-eating disorder (N=8), and other specified eating disorder or at a sub threshold eating disorder level (N=30). A sub threshold eating disorder level meant the participant had extreme concerns or regular eating disorder behaviour at a clinical severity level of 12. The participant cohort included women aged 18 to 42. The sample was

randomized into a control group, and an intervention group. The aim of this experiment was to investigate the experiences of help-seeking in a sample who had not previously sought treatment and who would be prompted to seek treatment as a part of the study. This would include identifying what services were used, what experiences were seen as helpful or unhelpful and what were the barriers to accessing services. To do this both groups (control and intervention) received contact information for specialized treatment and their individual eating disorder symptom profile, with the intervention group also receiving a prompt indicating that treatment could be helpful, and various information on self-help and treatment options. The control group eventually received this information at a later date. Through a mix of telephone interviews and questionnaires, at the 4-year follow-up, only a third of participants had sought help. Participants mainly pursued help from their general practitioner, followed by commercial weight-loss programs, and dieticians, psychologists, and psychiatrists.

A facilitator to a positive participant experience in help seeking was the empathy and rapport from their health professional (Evans et al., 2011). This entailed feeling free from judgment to speak about symptoms, or anything else related to their experience. Another factor that increased participant positive experiences was when these providers acted professionally, such as providing appropriate follow-up and referrals. Furthermore, participants articulated a negative experience when there was a lack of information given from providers. The participants had a negative experience in accessing care when they felt judged or stigmatized because of their disorder.

Participants were also frustrated when they felt their providers were not addressing their eating issue seriously, and when providers did not take the time to provide proper treatment (Evans et al., 2011). Also, participants felt more comfortable when dealing with a female

provider than a male provider in many scenarios. The three major barriers related to accessing care for participants in this study were the cost of treatment (in missed work pay), the time of treatment, and the strict entry criteria for certain services. There were also individual barriers mentioned in participant's lack of motivation to change, and feelings of shame.

Cachelin and Striegel-Moore (2006), examined treatment seeking for eating disorders in Mexican American and European American women. The sample was comprised of 76 Mexican American, and 69 European American women with mean ages of 27.8, and 28.8 respectively. These women had a range of eating disorder diagnosis such as anorexia nervosa (15 total), bulimia nervosa (53 total), binge eating disorder (47 total), and other specified eating disorder (30 total). The participants were phone interviewed twice. The findings showed similarity in barriers to treatment in both groups, but differences across groups in help seeking behaviours, and thus levels of diagnosis and treatment.

The barriers presented were mainly psychosocial, in that both groups did not seek treatment due to feelings of shame, believing one should be strong enough to help oneself, minimization of the severity of the problem, and a fear of being labeled (Cachelin & Striegel-Moore, 2006). Some other barriers were also not knowing where to go for help or not knowing what specific treatments were available, and concerns related to cost of treatment or lack of health insurance coverage (Cachelin & Striegel-Moore, 2006). The top five barriers identified by Mexican American women were: feelings of shame, not knowing where to go for help, believing that one should be able to help oneself, fear of being labelled as having an eating disorder, and not believing that one's eating problems were serious enough to warrant treatment. The top five barriers identified by European American women were: believing that one should be able to help oneself, not believing that one's eating problems were serious enough to warrant treatment,

feelings of shame, not knowing where to go for help, and finances or lack of insurance. The differences across groups were the fear of being labelled with having an eating disorder (major barrier for Mexican American), and the barrier of finances and lack of insurance (major barrier for European American). The primary reason for help-seeking differed in that more Mexican American women had sought treatment related to concerns of weight when compared to European American women.

The literature has a much larger emphasis on the barriers to eating disorder access and care than there are for facilitators. This opens up an opportunity for the current thesis to pay equal focus to participant facilitators, which will help in contributing to this gap in the current eating disorder scholarship. Finally, it is important to keep these discovered major barriers and facilitators in mind throughout the rest of the thesis. These study findings will help to inform and to provide a deeper context for comparison in this thesis' findings and discussion.

2.7. Gaps in the Research

There is a need for more research on all aspects of treatment for eating disorders strictly in a youth population. There is little data collected from just the adolescent/youth population, with most of the literature coming from either a mixed adult/adolescent sample or an adult sample alone. There are several challenges in adolescent/youth eating disorder research, such as recruitment and ethical considerations, which leads to fewer and smaller-scale studies (Lock, 2010). The majority of eating disorder research occurs in the adult population, which means the diagnostic criteria, studies, treatment, outcomes, and assessment standards are geared toward adults and not youth specifically (Lock, 2010). There are some study sites where the majority of adolescent/child eating disorder research is taking place, however this needs to continue to develop and expand to other locations (Lock, 2010). Also, there is a growing trend in engaging

patient voices in health care research (Fleurence et al., 2013). As seen in this literature review there is a need to include more participant voices into eating disorder research, which would help to shape future healthcare. The current study contributes to this evolving movement by having the participants' voices determine the research outcomes. Additionally, this study contributes to the field of eating disorder research by providing another example of using patient voice in healthcare research.

There is a gap in the qualitative literature exploring youth eating disorder experiences, and specifically experiences with barriers and facilitators to diverse forms of care. There were only a few articles that explored the adolescent perspective to care that were not in specific context of an inpatient treatment setting (Bezance & Holliday, 2013). Another gap was that only one of the articles reviewed represented both the youth and parent voice in their studies (Kyriacou et al., 2009). Furthermore, there is room for exploration of participant experiences in Atlantic Canada, as only one of the studies reviewed was in the context of Atlantic Canada. This study (Heath et al., 2006) is currently almost a decade old, furthering the support for an up to date exploration of participant experiences.

2.8. Chapter Summary

There are several options for eating disorder treatment for youth and their families, such as family-based therapies for youth having anorexia nervosa, and CBT for youth having bulimia nervosa (APA, 2006; Yager et al., 2012). However, many of the treatments being recommended come from clinical experience, and not based on the evidence (Yager et al., 2012).

When looking into the barriers and facilitators to mental health access, there was a plethora of studies and differing perspectives. When exploring these articles major barriers to accessing mental health care included: stigma (Aisbett et al., 2007; Boyd et al., 2007; Boydell et al., 2006;

Francis et al., 2006), a lack of knowledge of available services (Barker et al., 2005; Boydell et al., 2006; Rickwood et al., 2005; 2007) and a lack in recognition of mental health symptoms (Biddle et al., 2007; Thomson et al., 2014). Although there was not as much emphasis on facilitators, some mentioned were: having a positive past experience with services (Lindsey et al., 2006; Rickwood et al., 2005; Timlin-Scalera et al., 2003), having an experienced provider (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009), and having a provider who was empathetic and sensitive to the patient (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009). When focusing on the barriers and facilitators in access to eating disorder care there were fewer studies available. Some major barriers identified in this work included: psychosocial barriers (Cachelin & Striegel-Moore, 2006; Evans et al., 2011; Leavey et al., 2011), providers not being experienced in eating disorder care (Evans et al., 2011; Heath et al., 2006; Leavey et al., 2011; Tierney, 2008), waiting times (Heath et al., 2006; Leavey et al., 2011), a lack of resources and availability of care (Heath et al., 2006), feelings of shame and stigmatization (Cachelin & Striegel-Moore, 2006; Evans et al., 2011), and a lack of information supplied from providers (Evans et al., 2011). There were a few facilitators mentioned as well, such as health providers acting professionally and being empathetic (Heath et al., 2006; Evans et al., 2011), providers supplying helpful eating disorder information/options to the patient (Evans et al., 2011), having a multidisciplinary approach to care (Heath et al., 2006) and providers being knowledgeable about eating disorder care (Heath et al., 2006).

From reviewing the literature it is evident that there is a gap in the qualitative literature surrounding youth and parent experience in accessing eating disorder services. It is clear however that multi-perspectives act as a valuable source to understanding eating disorder research. The evidence suggests that one perspective may not be enough, and that including

additional perspectives holds value to the research findings, and study rigor (Heath et al., 2006; Kyriacou et al., 2009). Additionally, literature reflecting youth experiences in accessing services is generally very limited, especially within Atlantic Canada. Through the current study there is an attempt to add to the qualitative eating disorder scholarship in exploring experiences, and thus the barriers and facilitators to Atlantic Canadian youth eating disorder care.

The next chapter explores the methodology and methods used in this thesis. There is an explanation of the study paradigms, and how the design of the study ensures a high level of trustworthiness, credibility, and rigor. There is also a discussion of the data collection and analysis process.

Chapter 3: Methodology and Methods

The main study research question is: *What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?* The additional accompanying questions are: *What health services are these patient populations currently accessing? What services are they accessing through other agencies (e.g., education, social work, private sector providers)? What services are effective/ineffective and why?*

3.1. Paradigm: Qualitative Inquiry

It is important to define a study paradigm in order to help make visible how the research questions are formed and to demonstrate how various philosophical assumptions influenced the research process (Creswell, 2012; Guba, 1990). The main components of the qualitative inquiry paradigm revolve around ontological, epistemological, and methodological assumptions (Guba & Lincoln, 1994). The ontological assumptions are rooted in the perception of what the nature of social reality or how the social comes into being (Guba, 1990). Epistemology is focused on the relationship between the researcher and what is capable of being known, which is influenced by the researcher's ontological assumptions (Guba, 1990; Guba & Lincoln, 1994). The methodology is the researcher's approach to an inquiry and is guided by their ontological and epistemological choices (Creswell, 2012; Guba, 1990; Guba & Lincoln, 1994). Axiological assumptions are the ethics and values that the researcher brings to the study and how a researcher positions their self in the study (Mertens, 2010).

Several possible interpretive frameworks exist which include these philosophical assumptions, such as an interpretivist or pragmatic paradigm (Denzin & Lincoln, 2011). This project employed the qualitative paradigm of interpretivism, where the aim of the research is to

focus on the participant's view of the situation as much as possible (Creswell, 2012). In qualitative inquiry, theories are often inductively developed and emergent designs are used within context-specific inquiry (Schwandt, 2007). Choosing a qualitative paradigm is to also make ontological (social constructivism), epistemological (interpretivism), and methodological (narrative) assumptions that are in line with this paradigm. Indeed, the theoretical framework is also in line with the paradigm in that it is ecological and takes into consideration the many layers of contexts that impinge upon the barriers and facilitators negotiated by young people and families.

3.1.1. Ontology.

For this thesis project, the ontological belief is in a sort of social relativism based on the idea that the social world comes into being and is constructed by and between people and institutions where multiple local realities are constructed through lived experiences and interactions with others (Creswell, 2012; Guba, 1994). This assumption was supported in the thesis project across youth and parent cohorts as they viewed the topic of access to eating disorder services differently depending upon their unique experience. For instance, *Carl*¹ (youth) believed that the outpatient program was extremely inaccessible and that care was poor in this setting, where *Laura* (youth) found the program to be quite accessible and the care to be exceptional. Thus these varying experiences illustrate differing perspectives on the realities of the eating disorder outpatient program. Overall, these varying experiences illustrate diverse perspectives that must be interpreted in nuanced ways, to understand the multiple realities of access and care in eating disorder services in Atlantic Canada.

¹*All participants were given pseudonyms to ensure anonymity*

3.1.2. Epistemology.

A social constructivist ontology has guided the assumption of how reality is known in the current study and my interpretive epistemology has animated the need to interpret participant's experiences that have been co-constructed (Guba, 1990). This constructivist perspective indicates that individuals draw upon discourses that have meaning to them in order to create their reality. These various participant experiences have been articulated to me and I have co-interpreted them by highlighting recurring themes and reflecting on the current knowledge related to these areas in the literature. The rigorous process of creating these overarching themes and narratives is detailed below in the Data Analysis section. Through meeting with several youth and parent participants, there was negotiation and discussion concerning what the real issues are, and how as a researcher I might interpret these. For example, several participants had alluded to the need for psychological support for eating disorder treatment, and that this support was rarely accessible in a timely fashion through public coverage. Through further dialogue it appeared that most participants had attempted or had accessed a private psychologist, who cost them out of pocket, and at times this psychologist was ill equipped to treat a youth who had an eating disorder. Through these conversations, it was clear that a recommendation for an increase in public coverage for psychological care and an increase in practicing psychologists specializing in eating disorder treatment was appropriate. This is just one instance where much dialogue with both participant groups provided for a more nuanced understanding of their experience and a co-construction of meaning and recommendations. The recommendations for the study are derived directly from these participant interviews with an added layer of interpretation from the researcher. However, when exploring and critically analyzing all of these experiences, a

complex, holistic account of the eating disorder health care “system” in this Atlantic Canadian province has been generated for discussion.

3.1.3. Methodology.

The approach to inquiry in this framework is in line with the ontological and epistemological assumptions through using an inductive method of emergent ideas, which has been generated through direct interactions between the participants and myself (Guba, 1994). A narrative inquiry was perfectly situated as the ascribed methodology (Smith & Campbell, 2012) due to the fact that in studying narratives, researchers can truly explore how humans experience the world (Connelly & Clandinin, 1990). This was one reason why narrative inquiry was the methodology leading to the narrative journey interview utilized to collect and analyze the participant stories in the current study. These expressed, lived stories have been collected from and with participants through a one on one interview, with participant demographic information being collected as well (see Appendix B and F).

There are several forms of narrative inquiry. This thesis employed a personal experience narrative, which is a form of a life history approach, allowing for study of an individual’s personal experience in their various dealings with the eating disorder system (Chase, 2005). This personal experience narrative maintains a similar biographical form to other narrative approaches such as a beginning, middle, and end, but differs in that the focus is on a shareable experience; including single and multiple, and private and communal episodes (Chase, 2005). This narrative structure of a beginning, middle, and end also acts as a chronology for each participant, as was the case in the present study. The current narratives are generally formed in a similar manner; they start with a description of the beginning when an individual initially recognized they may need help for their mental health. This is followed by an exploration of the participants’ journey

to accessing health care, and experience within the health care setting. Next in the narrative is how the school had been involved in the participant's journey. This was followed by the participant's current status regarding if they were on a path to recovery, still seeking support, or not following up with health care support. The narratives typically end with the participants' recommendations, and perspectives on what an ideal journey through the health care system would look like. A summary of these narratives can be found in the Findings chapter, however the full narratives have been removed in order to prevent participant identities from being recognizable. This form of narrative analysis involved narrative reasoning through an in-depth exploration of each participant story to form their chronological narrative (Polkinghorne, 1995). In addition to this narrative analysis for chronology, thematic analysis was a second form of analysis used in the present study. These themes were extracted from participant stories and across groups of narratives, in a similar approach to Riessman's narrative analysis (2008). Some themes generated through this process included timing and geographical location of programs, waiting periods, turning points, and psychological services. The thematic analysis process has been extensively detailed in the Data Analysis section below and illustrated in Figure 2.

3.2. Researcher's Standpoint

Knowledge of researcher reflexivity and standpoint is important to understanding how the study findings have been collected and interpreted (Creswell, 2012). My connection to this area of research comes from a both a professional and personal context. I am connected to someone who has had an eating disorder. Through sharing the experiences with this individual I have obtained a fairly comprehensive account of how the healthcare system in the province is constructed for those who have an eating disorder. From the inception of this study, I have also positioned myself in the eating disorder network throughout the province. I have made

connections with the local eating disorder advocacy association, attended monthly webinars at the outpatient treatment centre, sat at the Provincial Government Eating Disorder Roundtable, and am a member of the Eating Disorder, Disordered Eating, & Body Image Research Exchange Group. I was also involved in the Provincial Government Eating Disorder Roundtable. This was an activity where the current eating disorder environment was discussed between various health care authorities, government officials, and other individuals who are positioned in the provincial eating disorder community. I have read extensively on the topic and have been exposed to scholarly literature, policy and practice in the field. This position has assisted with the valuable standpoint that built credibility for access to and discussions with participants. It has also improved the trustworthiness of the interpretations; as I was able to compare the specific and general themes emerging to that of the larger field of eating disorders, and to understand when they were the same or different from current wisdom.

3.3. Sampling Strategy

In order to fulfill a purposeful sampling strategy there are three main considerations: who to select for the study, the type of sampling, and the sample size (Creswell, 2012). In looking at who to select for the study there have been two categories of participants defined. The participants were selected because they all met the criteria of being intimately involved with the youth eating disorder system, and this has formed a homogeneous sampling (Marshall, 1996). The first category included individuals with a self-reported diagnosis of anorexia nervosa or bulimia nervosa, and who utilized a related health service in Atlantic Canada while between the ages of 15-24 years old. This self-reported diagnosis can come from any number of clinicians, which has potential to impact the findings surrounding access, and who was able to take part in

this study. These participants varied in an assortment of demographic information. The second category of participants included parents of youth individuals in the first category.

The next consideration is type of sampling. A criterion sampling strategy was employed in order to adhere to the inclusion criteria within the two categories of participants. However, snowball sampling was also utilized in order to identify potential participants who were rich sources of information. Also, through sampling in different cultural, educational, and socioeconomic backgrounds, a form of maximum variation sampling was used as well. The sample size is the final consideration for a purposeful sampling strategy. It is necessary to collect enough information to understand the depth and breadth of access to eating disorder services (Rudestam, 2007). When the development of the study concepts has been reached, it is said that a saturation of data has occurred and collection of new data can cease. The aim of the study was to develop a collective story from a scope of sources, developed through a narrative approach. Through discussion with my thesis committee, a sample size was theorized to aim for 12 participants, which turned out to be 11 participants used, due to data saturation being reached. In a narrative inquiry, sufficient information can be attained from one or two participants, however the availability of these rich stories encouraged the use of more participants to attain an even deeper understanding of these experiences (Creswell, 2012).

3.4. Recruitment Strategy

Outreach to various stakeholders occurred in order to increase understanding of the eating disorder community, and to connect with potential participants. These various gatekeepers and key stakeholder groups included an eating disorder advocacy organization, an eating disorder outpatient program, a research exchange group, and the Provincial Government Eating Disorder Roundtable. Recruitment had been organized amongst the project coordinators, and other

members of the research team, as this study is a sub study under the larger ACCESS-MH project. The information attained in the current study is also being utilized in the ACCESS-MH project, meaning there is a high level of organization and coordination occurring as to ensure appropriate participants are involved. This allows for an even disbursement of participant cohorts across the Atlantic Provinces. Selection of these participants was based on a first come, first served basis, as long as participants fit the inclusion criteria.

After initial contact from participants occurred, the ACCESS-MH project manager connected with the participant to arrange an interview time. Following this, a more in-depth description of the project, and consent form was provided to the participant prior to entering the sessions (see Appendix A, E, I, and J). This study has been designed for a single participant interview, with the option of a follow-up interview as a part of the ACCESS-MH project and discourse. It is anticipated that the follow-up interviews will take place approximately two years after the initial interview, however these interviews are not a part of this thesis project. This recruitment strategy is congruent with the sampling strategy of purposeful sampling, and with the current narrative methodology.

3.5. Data Collection

After support from my thesis committee was obtained, and following institutional and multisite ethics approval, participant recruitment was allowed. I personally carried out all recruitment, data collection, raw data transcription, and analysis. For the current study, the data collected from each participant included a demographic face sheet (see Appendix B and F) and a one on one interview. In regards to procedure, the study was explained when the participant arrived, and informed consent was gained (verbally and written). The participant was also given the opportunity to fill out a face sheet with their demographic information. This allowed for

collection of information objectively regarding cultural, socioeconomic, and health status, among other items. The interviews lasted from 40-150 minutes and were audio-recorded. They were loosely guided by four main themes: early signs (retrospective); entering the system (or not); exits and returns; and recommendations and directions (prospective). There was an interview protocol prepared in advance, which was used as a guide for drawing out specific participant experiences (see Appendix D and H) (Tilleczek & Bell, 2014). These questions were not strictly followed, but were listed to help guide the participant to reflect on the phenomena of study. Initial questioning was focused on discovery of information, followed with subsequent probing questions in order to bring more depth to the issues. Supporting documents used during the interview can be found in the Appendices (see Appendix G, and K to R).

Field notes were taken before each session, throughout the interview, and at the end of each session, which added to a supplementary source of information. These notes were referenced throughout the individual participant narrative synthesis, and in other parts of the data analysis. Youth participants were remunerated with a \$30 honorarium for their time and parents were offered reimbursement for their travel and childcare.

3.6. Conceptualization and Definitions

Two important definitions that need to be explained are the terms barriers and facilitators. In the present study, a barrier is defined as anything that impedes an individual from receiving or accessing care, including; geographical distance, lack of appropriate care providers such as psychologists, and lack of services provided (Jacobs, Ir, Bigdeli, Annear, & Van Damme, 2012). Barriers can also be psychosocial or individual characteristics such as fear of lack of control, and stigma, which may prevent one from seeking any services (Evans et al., 2011; Leavey et al., 2011). For the purposes of this study facilitators, on the other hand, are defined as anything that

helps an individual to access care, such as service awareness, a trustworthy provider, or an easily accessible location (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015).

As defined by the United Nations (2014), a youth is considered someone between the ages of 15 and 24 years old. All of these participants had self-reported to having been formally diagnosed with anorexia nervosa or bulimia nervosa from a health care provider, and in most cases this was from an adolescent medicine specialist. Additionally, all of the participants utilized a specialized eating disorder health service in Atlantic Canada. A parent was defined as the primary caregiver for the individual who had an eating disorder and accessed services in Atlantic Canada. These parents explained that they were intimately involved in their child's eating disorder journey.

3.7. Theoretical Framework

At times, a theory is not always valued at the start of inquiry, but is inductively developed and adapted in process of the qualitative research (Creswell, 2003). This is the case for both the larger ACCESS-MH study and for the current thesis, where the ecological complex cultural nesting theory (Tilleczek, 2011; 2014) will be adapted over time in the study and is used to guide interpretation of the narrative analysis and to construct the recommendations from the study data. The complex cultural nesting framework builds upon Bronfenbrenner's (1979) ecological framework of human development and takes into consideration the development of young people and their families in relation to their social contexts and environments. This development is categorized into six social ecological contexts, each describing a different set of parameters: individual, the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1979). The premise of the complex cultural nesting theory is that youth development occurs as a set of social processes that are nested in a variety of contexts that hold

opportunities and constraints over time and place. The theory highlights narrative, biography and society as critical dimensions of young lives (Tilleczek, 2014; Tilleczek et al., 2014).

The theory is also derived from the sociological imagination of C.W. Mills (1956) that makes the necessary connections between becoming (history), being (time), and belonging (society) for young people (Tilleczek, 2014). The use of this interpretive framework allowed for a heightened understanding of the narratives as individual human experiences within larger cultural contexts and not as separate fractured experiences.

For instance, this research found that many participants spoke about the struggles they had with their eating issue in a variety of environments, such as at home, in the hospital, and in school. For example, *Yvonne* (parent) spoke about how the social engineering of schools placed an increased level of social anxiety on students and *Rosie* (parent) spoke about the influence the school had on her child's mental health, also alluding to structural changes, such as providing more safe school space for students, which could enhance mental well being. A participant dyad spoke to the obesity discourse, and how schools are focusing on health equating to not being "overweight", which can have further implications for developing disordered eating and body image issues. This point is also discovered in the literature (McVey et al., 2008). They also alluded to health curriculum focusing only on physical health and leaving little room for mental health education. These social forces in education had a significant influence on youth believing they were *being* healthy but they were actually *becoming* sick.

Youth, such as *Laura* and *Tom*, felt that they did not *belong* to any social group, with many other participants echoing similar stories of isolation, and feeling like outcasts. In certain scenarios social forces acted in an opposite, and even paradoxical manner, such as the eating

disorder outpatient program, and the hospital. Multiple participants articulated that these mesosystems could help youth *become* healthy, and help youth *become* sicker.

Each individual narrative was circumstance dependent. But, it was also clear that the youth participants were constantly interacting with these systems and there was bi-directionality in each of these relationships. These interactions are illustrated in Figure 1 which demonstrates how the complex cultural nesting theory was used to interpret the narrative journeys of the participants in the thesis by exploring how history, time, and society combined with individual identities, relationships, and lives through a number of nested systems. It also helps explore how the individual youth and families must negotiate a system that provides both opportunities and constraints (barriers and facilitators) to their well-being (Tilleczek, 2014).

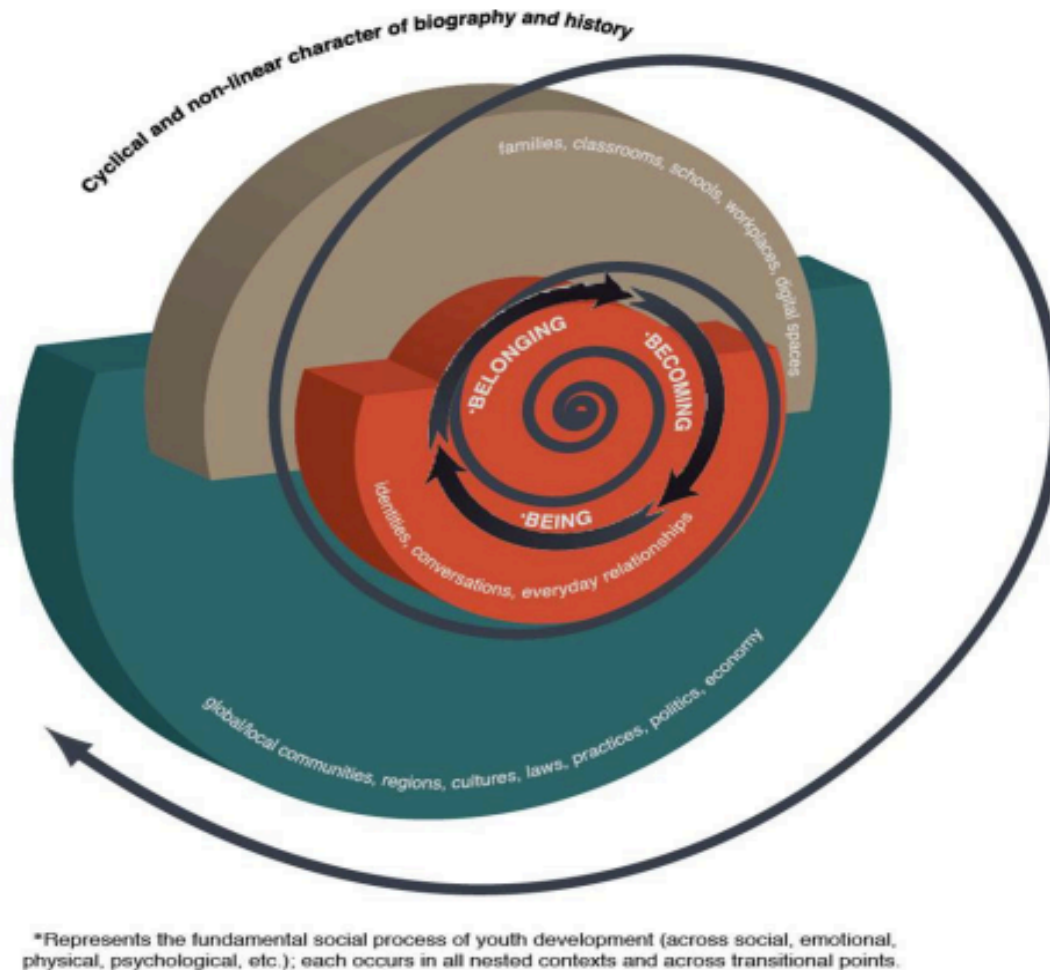


Figure 1. Complex cultural nesting theoretical approach (Tilleczek, 2011; 2014)

Caption: The Figure illustrates the microsystem in the centre as nested within the meso and macro systems while the spiral depicts the individual narrative journeys that are taken across these systems. The non-linear character of biography and history encompasses them all.

In targeting recommendations through the various levels of child development, we ensure that the subject of access to and care in eating disorder services is addressed thoroughly from different angles, and different contexts. The exploration of access *with*, *for*, and *by* youth and their families, through extensive interviewing, continues to support the theoretical approach of the complex cultural nesting theory (Tilleczek, 2014). This approach allows recommendations to

be created through “an understanding of the complex cultural nest of young people and their intersecting, complex, contemporary lives” (Tilleczek & Campbell, 2014, p. 65).

In order to understand the theory behind the study recommendations, the following is a more in-depth exploration into these six categories of human development, followed by how these categories have been appropriately adapted for the current study. The individual is the first class and is at the core of the framework, having his or her own thoughts and beliefs. The next context is the microsystem, which involves interpersonal relations with people who most directly, and immediately impact the individual (Bronfenbrenner, 1979; Tilleczek, 2011). These microsystems involve a variety of people who are in constant contact with the individual; family, peers, educators, and depending on circumstance, health care providers. The mesosystem consists of interconnectedness between various microsystems, such as the family with health care providers, or other health care providers amongst themselves (Bronfenbrenner, 1979). The exosystem is the next social level, which the individual has no immediate connection with, but decisions made at this level may trickle down and have an indirect effect on the individual (Bronfenbrenner, 1979). An example of this could be a new health policy being created, which may influence care for the individual. The macrosystem is the highest level of influence on the youth’s development, and Bronfenbrenner (1979) describes it as,

consistencies, in the form and content of lower order systems (micro-, meso-, and exo-) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies. (p. 26).

The chronosystem involves the timing and patterning of lives allowing the concentration on timing and history in context of the developing individual and their ever-changing environment (Bronfenbrenner, 1979).

In framing recommendations for this thesis, an ecological framework has been used to interpret the data as follows, the individual is the youth participant, or from now on will simply be referred to as the youth. The microsystem consists of interactions the youth has with peers, family, and care providers. The mesosystem consists of interactions the youth has with health care services such as the outpatient program, or the adolescent eating disorder service. The exosystem is targeting the provincial government departments, specifically the departments of Health and Community Services; Senior, Wellness and Social Development; and Education and Early Childhood Development. The macrosystem recommendations revolve around ideologies relating to the societal culture of eating disorders, and mental health. The chronosystem refers to recommendations associated with timing associated with the youth's journey from their initial recognition of an eating issue up until when the interview occurred.

3.8. Methodological Congruence

This thesis research has methodological congruence. According to Morse and Richards (2002), there should be interconnectedness between the purpose, questions, and methods of research. Four areas necessary for methodological congruence are: document, procedural and ethical rigor, along with auditability (Burns, 1989). A number of strategies have been employed in order to maintain a high level of methodological rigor in the current study.

Additionally, there are rules to consider for supporting a good narrative study. The first is that the participants' fit within the inclusion criteria; in the present case this means each participant is a representative of the culture-sharing group of youth who have an eating disorder, or their parent. The next concept is that sources of bias are available, including bias from participant, researcher and the participant-researcher interaction, which has been the case through the section titled Researcher's Standpoint (Creswell, 2012). Another requirement is

properly developing a chronology, which connects different parts of the story and occurs through each of the participant created narratives. Lastly, the study should voice what the participants said, and how this was said, which occurs through the narrative and thematic analysis sections (Creswell, 2012). In this thesis I have strived to ensure that all of these principles were followed.

3.8.1. Document Rigor.

Document rigor is the presentation of all study elements, in a clear and organized manner (Burns, 1989). In this thesis, elements such as the study purpose, research question, significance, and literature review have been presented in the Introduction and Literature Review chapters. The research paradigms have been discussed at length, and the data collection, sampling and recruitment strategies are available in this Methodology and Methods chapter. In the following chapters other elements are presented including my data analysis, interpretation, and application of findings in the context of theory and the literature, and future directions and recommendations. The ethical considerations for the study have been discussed in this Methodology and Methods chapter, and have been explored at five university Research Ethics Boards as a part of the ACCESS-MH project. All of the documents used for the study, and samples of the documents used for the data analysis have been included in the Appendix. My credentials and standpoint are available throughout the study (see Researcher's Standpoint), and the study has had significant oversight from my supervisory committee, and other members of the ACCESS-MH project. All of these study elements are present, and adhere to the academic standards (Burns, 1989).

3.8.2. Procedural Rigor.

Essential to a high level of procedural rigor is that the researcher executes the research process as intended. This means the researcher records the steps they have taken to confirm

accuracy in the data collected. Also, this includes the data collected to be representative of the intended culture-sharing group, which is youth who have accessed specialized eating disorder services, and their parents (Burns, 1989). The use of field notes in this study helps to view how the project was carried out, and if there was deviation from the proposed protocol. I was well trained at a variety of qualitative workshops, and in an advanced qualitative research course, ensuring my ability to conduct a one on one interview was appropriate. I was the sole collector of data for the study and was appropriately positioned to do so. There was also a manual developed that clearly outlined procedures for all phases of the research study, which were adhered too (Tilleczek & Bell, 2014).

The interviews were a semi-structured form, and although there was an interview guideline, I was encouraged to go with the flow of the conversation. The major themes were covered in all of the interviews. Many of the conversations contained rich information that could be tied into appropriate information for the study. Due to the large number of diverse interviews there is a heightened trustworthiness in the accuracy of the participant's voices. The participants selected were appropriate for the questions, and there was sufficient data gathered in the collection phase. The procedure was universally consistent for all participants, with equal levels of engagement regardless of differences in participants' status. All participants held high levels of credibility, as they had personal experiences with eating disorder services as a patient or parent. Additionally, there was appropriate entry into the eating disorder community through a variety of gatekeepers such as the eating disorder advocacy group, and research exchange group (Burns, 1989). My entry into this community was widely accepted by members, and there was an appreciation for the nature of this study.

Also two other methodological considerations were ensured: adequacy and appropriateness of the data (Morse, 1998). Adequacy of data refers to collecting an appropriate amount of information. Through collecting data from various participants, there was a wealth of information collected in this study, with the information starting to show conceptual and content overlap. The various study concepts could be developed from the information collected and there was a clear understanding of the information in the context of the research questions, thus we could say with certainty that a saturation of data was obtained (Creswell, 2012). This indicates that adequacy in the dataset was achieved. Appropriateness of the data was also achieved through purposeful sampling of several different types of participants. All of these concepts have increased the trustworthiness in that the information collected was carried out with a high level of procedural rigor. Tied into this procedural rigor concept is dependability in that if other researchers followed the same means of procedural rigor applied in the current study there would be similar findings if circumstances were similar (Rudestam, 2007). This is explored in more detail below in the Trustworthiness section.

3.8.3. Ethical Rigor.

Ethical rigor was maintained throughout the research process. Full Research Ethics Board approval was obtained from all five universities involved in the larger ACCSS-MH project, which the current study falls under. This process was rigorous, and all documents and protocols hold identical content, unless changes were made in order to accommodate for the differing ethics authority. Ethical approvals for the current study was located as an Appendix, but has been removed in order to protect possibly identifying the province in which the study was located. Participants were well informed about the study procedures, and how the results would be used. Participant rights were also clearly verbally articulated, and presented through written

documentation (Tilleczek & Bell, 2014). There was a full level of respect for participants' rights, and the data collection environment was safe and open. Other sections of this thesis discuss various concepts related to ethical rigor as well, including the sections below: participant risk, informed consent, anonymity and confidentiality, and data storage.

3.8.3.1. Harm and/or potential risks to participants.

There was a psychological risk in the current study, as the participants were discussing a time that was possibly very difficult and emotional for them. There was a chance they might have felt anxious during the interview and may have wanted to stop or not answer certain questions. It was clearly stated to the participant that they had the right to stop the interview at any point, where no further questions were to be asked and no explanation was needed. Fortunately, no issues arose in the current study, but the protocol for a youth in crisis can be found in Appendix Q. There was appropriate training associated with the use of this protocol, as well as opportunities for post interview debriefing sessions as well.

3.8.3.2. Informed consent.

Informed consent was obtained through verbal acknowledgement and through a written, and signed paper document. The consent form can be found in the ACCESS-MH Manual (Tilleczek & Bell, 2014) and also in Appendix E and J. Consent was necessary to interview the participants, in order to audio record the interview, and to use the collected information for this Master's Thesis and for the larger ACCESS-MH project. There were assent forms specific for the minors to be interviewed, along with consent forms specific to legal guardians found in Appendix A and I. As presented in the consent form, participants were notified of their right to stop the interview, withdraw from the study, or not to answer any question. This was also verbally reiterated to the participant.

3.8.3.3. *Anonymity and confidentiality.*

The participants were informed that I would remove all personal identifying information from their interview. Participant confidentiality and anonymity was ensured throughout the entire process including recruitment, data collection, data analysis, and research dissemination. The graduate student transcribed the audio recordings, and “washed out” identifying information throughout the analysis process. This “washing out” involved removing any names, identifying information, service names or locations, and other items that may lead to identification of the participant. The participants’ information is stored in association with an alphanumeric code, with only the research team having the identifying match between code and participant identity. In the analysis process, participants were given pseudonyms for their narratives in order to ensure anonymity and confidentiality, while ensuring participants were not referred to simply as a number, but as a person with a name. As much information as possible that could lead to identifying the specific province in which the research took place was removed in order to help ensure that individuals could not be recognized.

Since the study is positioned in a relatively small community there have been extra measures taken in order to protect participants’ anonymity even further to avoid the potential negative repercussions from identification of participants. These measures involved a process of “scrambling” the 11 participant’s descriptors such as gender, age, name and other variables. Youth participants have been engaged in the youth health care system for treatment of their eating disorder. However, in the write up of this thesis the age of participants has been altered or removed in order to take the additional steps to avoid possible identification. The pseudonyms associated with participant are also randomized, and do not necessarily represent the true gender of the participant in attempts to also avoid identification of the participant or their family. In

addition to these changes and alterations in the participant's narrative summary, the participant's full narratives have been removed from the Appendix of this thesis in order to further protect the identities of these participants. These narratives have been developed from the interview data and are an essential part of the study rigor and in providing the voice for each participant. However these cannot be shared in the thesis due to the risk of being able to identify participants from their full story. In the presentation of the data, I have adhered to developing an ethic of protection of identity while also providing a full voice to the participants.

3.8.3.4. *Storage of data.*

The information is stored on an external hard drive that is password protected. The information files are encrypted, and labelled with an alphanumeric combination. These are housed at the Young Lives Research Lab- University of Prince Edward Island for secure storage and translation. This safe storage of the information will continue for a minimum of 15 years following the completion of the project.

3.8.4. Auditability.

Auditability is the creation of documents that can show how decisions were made regarding data analysis and the generation of findings. This could be an in-depth series of recordings, transcripts, and coding protocol to provide for a decision trail easily understood by others (Shenton, 2004). This concept known as an audit trail was maintained for the present thesis, and parts of it can be found in the section describing the Decision Making Process for Thematic and Narrative Synthesis. In addition to the aforementioned components of an audit trail, there was also the use of field notes in the study, which provides some more insight into the auditability process.

3.9. Trustworthiness

The merit of qualitative inquiry is evaluated by the assessment of the studies' trustworthiness (Morse, Barrett, Mayan, Olson, & Spiers, 2008). In quantitative research, studies are evaluated based on their reliability and validity, however in qualitative research a more appropriate means of evaluation is through trustworthiness (Shenton, 2004). Guba (1981) originally proposed that there were four constructs of trustworthiness in qualitative studies that are comparable to the evaluative components of a quantitative study, these are: credibility, transferability, dependability, and confirmability.

3.9.1. Credibility.

Credibility is establishing how consistently the study findings are with reality such that the phenomenon under inquiry has been accurately captured (Merriam, 1998; Shenton, 2004). In the current study, this was accomplished in a variety of ways. First, the protocol developed for the interviews, such as interview question guidelines, and data collection techniques adhere to those developed for the ACCESS-MH project (Tilleczek & Bell, 2014). These protocols have been developed in association with current and appropriate literature for youth mental health research, and child-centered participatory research (Cappello, 2005; Carter & Ford, 2013; Clark, 1999; Mitchell, 2006; Tilleczek et al., 2014). Also, a prolonged engagement with the culture-sharing group is observed to increase credibility (Shenton, 2004). This has been the case with the current study, where I have spent time over the past two years connecting with the eating disorder outpatient program, eating disorder research groups, provincial government eating disorder roundtables, and with the local eating disorder advocacy organization. I have spent time with someone personally close to me who had an eating disorder, and thus have spent time observing eating disorder services in this capacity as well. In addition to this prolonged engagement in the

eating disorder community, I have endeavored to acquaint myself with the current literature in this area and in the context of Atlantic Canada. Credibility has also been increased through triangulation from data sources in the current study. This is due to a range of participants being interviewed in two distinct cohorts, as youth and parents. These viewpoints and experiences have been verified against each other, and have allowed for a true understanding of the perspectives surrounding accessing eating disorder services (Shenton, 2004).

Rich and detailed descriptions of the phenomena under study can also add to the credibility of a project (Shenton, 2004). There has been a significant effort made to detail youth and parents journeys in the current study. This has been multi-leveled, through individual narrative and thematic analysis for each participant, and then through interpretation of themes across participants. A thick description of access to and care in eating disorder services has been possible through the rich stories collected from participants, and rigorous means of analysis and interpretation.

Another important point to note is that the current study findings have been examined in relation to literature in the field, which can be found in the Discussion and Recommendation chapter. Lastly, the credibility of the researchers must also be considered (Morse et al., 2008; Shenton, 2004). In the current study, the primary author is a graduate student positioned in an Atlantic Canadian university, under guidance from two supervisors and two committee members. These supervisors and committee members are credentialed academics in a university setting: as professors and researchers in the fields of sociology, psychology, economics, and health care, and as directors of research units, laboratories, health professional education centres, and academic programs.

3.9.2. Transferability.

Transferability is focused on how the study findings can be replicated in other circumstances or environments (Shenton, 2004). It is important to note that the findings from qualitative studies, and as such this study, are not generalizable. Current findings are connected to a certain population of individuals operating in the context of the publically administered health care system in Atlantic Canada. The nature of qualitative inquiry is to develop interpretations and theories that are relevant to the participant populations studied, which has been the case for this thesis. The data used in this study reflect the experiences of individuals who were willing to participate in the study, and who were recruited through various organizations connected with eating disorders. The views of these participants may not be entirely representative of all individuals who have accessed youth eating disorder services in Atlantic Canada. Some steps followed in order to satisfy this construct of trustworthiness included providing an extensive background for the study in the Introduction and the Literature Review, along with providing a detailed description of access to eating disorder services in the Findings and Discussion (Shenton, 2004).

3.9.3. Dependability.

This construct reflects similarities to the positivist concept of reliability, in that if the study were to be repeated in a similar manner as ascribed, similar findings would be attained (Shenton, 2004). There has been a detailed explanation of the protocol for collecting the data in the current study, which is located in this chapter, and also in the ACCESS-MH manual (Tilleczek & Bell, 2014). Also there has been consistency in the coding of the data through a systematic recording of data, transcribing of data, and analyzing data, with a meticulous production of field notes. I have carried out all of the data collection, coding, and analysis in order to ensure consistency.

Along with these actions, a clear audit trail was created that outlined how conclusions were made regarding the narrative and thematic analysis, which has been detailed in the Data Analysis section (Shenton, 2004). This audit trail also included the raw data, forms of researcher reflexivity, an interpretation of how the researcher's reflexivity could bias the research process, and decision-making processes.

3.9.4. Confirmability.

The concept of confirmability is the qualitative investigator's comparable concern to objectivity. Here steps must be taken to help ensure as far as possible that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. (Shenton, 2004, p. 72).

As mentioned previously there has been a triangulation of data sources, from two participant cohorts, ranging in a variety of socio-demographic characteristics, which can help to reduce the effect of investigator bias (Creswell, 2012; Shenton, 2004). Also, in the section titled Researcher's Standpoint, I have been transparent as to my beliefs and assumptions surrounding eating disorder services, and have described my positionality. This helps to improve reader interpretation of how the data has been shaped by my beliefs, and the reader will be better able to understand how theory was supported, and be able to note potential bias (Creswell, 2012). Also, there has been a discussion of the methods limitations, and study strengths in the discussion chapter, which reinforces confirmability (Shenton, 2004). Additionally, through a clear audit trail, detailed methodological description, and figures outlining the data analysis process (Figure 2. And 3.), on top of the other examples of confirmability, there is plenty of opportunity for individuals to interpret the confirmability of the research findings (Guba, 1981; Shenton, 2004).

3.10. Data Analysis

Organization of data occurred through a rigorous process, which is described in the section below using Decision Making Process for Thematic and Narrative Synthesis. The analysis phase started with reading over the transcripts several times, making initial notes and referring to the corresponding field notes (see Figure 2.). Themes were eventually extracted, with this process being described below. The narrative analysis for this study focused on creating individual participant chronology narratives, and then proceeding with a thematic analysis from each participant, and across participant groups. The analysis for this study was two-fold: meaning coding and interpretation for chronology and themes. First, a chronology of each participant's journey through the health system occurred from analysis of his or her interview. This was focused on epiphanies and events in the participant's journey (Creswell, 2012). In addition to this mapping of specific participant events, a thematic analysis of the data occurred. Both fieldwork and analysis occurred simultaneously. No secondary data was utilized.

3.10.1. Decision Making Process For Thematic And Narrative Synthesis.

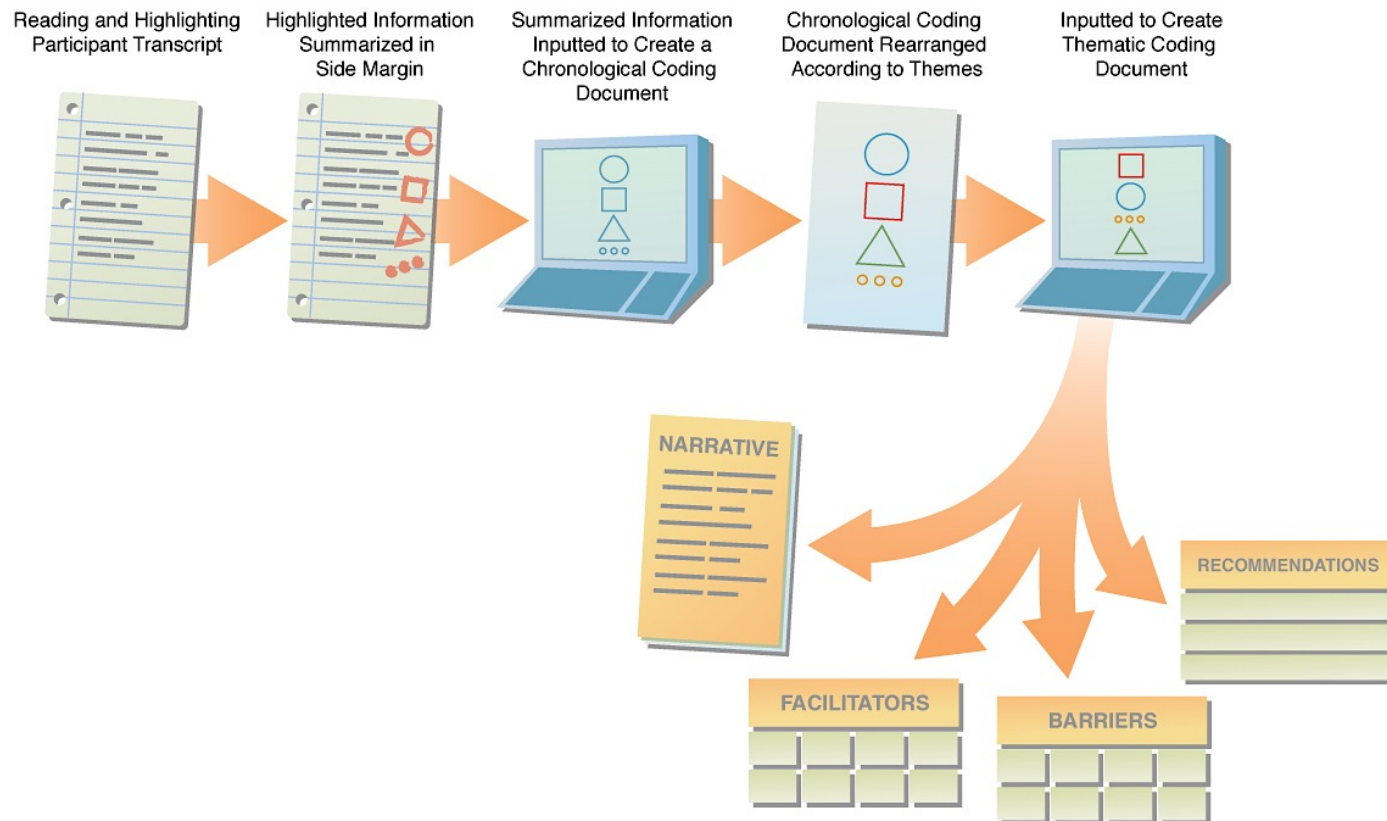


Figure 2. The Data Analysis Process

Caption: The Figure shows the process of analyzing the participant transcript to highlight appropriate findings, and then create documents, which capture and organize these findings. These findings are the basis for creation of the participant narrative and various participant tables.

3.10.1.1. *Thematic analysis.*

The same process was followed for each of the participant interviews regarding how themes were drawn from the transcripts. The process of narrative research analysis focuses on “interpreting texts that have in common a storied form” (Riessman, 2008, p. 11). Polkinghorne (1995) and Riessman (2008) advocate a similar approach to narrative thematic analysis as I am

about to detail. First, each interview transcript was first read with the intention of gaining a better understanding of the journey as a whole. Following this, the transcript was read through with sections of the text being highlighted (see Figure 2.). These sections were deemed to be important parts of the participants' story, ranging from experiences with healthcare providers, to emotionally charged events, recommendations, involvement with the education system, family support, and a variety of other aspects. After the entire transcript was highlighted, it was read through again and summaries were made in the side margins of the transcript, represented by a circle, square, triangle and three dots in the illustration (Figure 2.). For one parent participant, some of these summaries or side notes included: "Child continued to wear baggy clothes and exercised excessively, doing 200 sit-ups in the morning" and "The participant noticed his child becoming withdrawn, and 'he didn't talk a lot.'" These notes summarized the various highlighted areas of the transcript. These summaries could indicate an important quotation a participant mentioned, or could be a sentence or two describing what was highlighted. Following this process, these various margin summaries, and notes were inputted into a Word document for each participant labelled "Chronological Coding." This method of analysis was appropriate for the study, and the researcher was most familiar with this method of analysis. To provide a better idea of what this looks like one of the participant's chronological coding documents and thematic coding documents was included as an Appendix, however these were later removed in order to ensure the protection of the participant's identity. After the completion of compiling transcript summary notes into a word document, the document was printed. This signified the initiation of the thematic analysis process.

The thematic analysis process started with colour-coding each specific summary of the printed chronological coding document (which also included participant quotes) in

correspondence to a list of determined themes (see Figure 2.). For the majority of the journeys, the recurring themes were early signs, entering the system, returns/exits, participant perceived issues, positive notes, school/community activity, recommendations, and part of the story. One additional topic explored in each interview was the participants' perceived ideal journey. This included the participant retrospectively creating an ideal journey for his or her own experience. This ideal journey was reconfirmed with the participant after it was articulated. Some of these themes were based on the interview guide (Tilleczek et al., 2014), however some of these themes were developed inductively. This was to ensure the themes were appropriate for the voiced participant experiences. In the case where one summary fit under various themes, it was colour coded to each appropriate theme. Such as the following note from one participant's document, which fit under early signs and participant perceived issue, "Doctor filled out the form and said according to the form the child may be a bit under the criteria for the outpatient program, but sent it off to them anyways- Participant was confused."

It is important to know the decision making process in how each margin note was separated into each specific theme. A more in-depth exploration of the decision making process for classifying each theme can be found in the subsection below. These various summaries were colour-coded according to each specific theme, and this new "Chronological Coding" document was used as a template to create a "Thematic Coding" document. This process is observed in Figure 2 through the circle, square, triangle and three dots changing from blue to a variety of colours. This thematic coding document was similar to the chronological coding document, however it was reorganized for each theme to become a sub heading, with the various margin summaries placed appropriately underneath.

Between using both the chronological and thematic coding document, a clear and comprehensive picture was attained of how different pieces of the journey fit together. These documents were used to create each participant narrative, and each participant facilitator, barrier and recommendation table (see Figure 2.). The next level of thematic analysis occurred after all the narratives had been completed, this process is illustrated below in Figure 3.

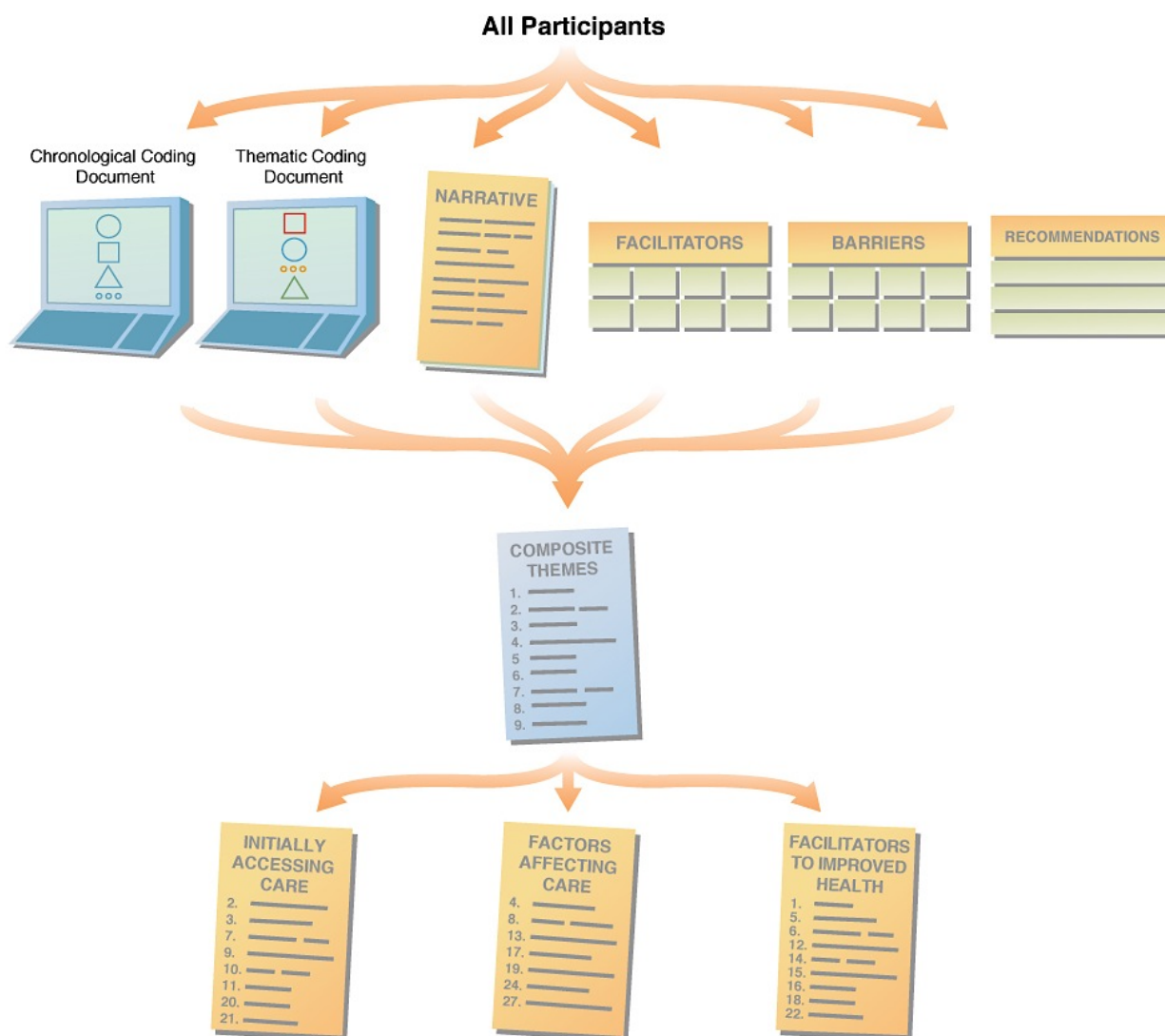


Figure 3. Analysis of Major Themes

Caption: The Figure shows how the three major thematic categories were created. This included analyzing the various individual participant documents for all of the participants, and then

creating a list of composite themes found in the majority of the participant documents. This composite list of themes helped in recognizing and creating overarching themes.

A composite list of major themes was created thorough revision of participant chronological and thematic coding documents, narratives, and facilitator, barriers and recommendation tables (see Appendix S and Figure 3.). This list was created from identifying themes that were found in multiple participant thematic documents. Each item in the list was linked to a specific participant reference or quote. This composite list of themes was then further divided into three major categories: 1) Initially Accessing Care, 2) Factors Affecting Care, and 3) Facilitators to Improved Health. The various themes were then placed under the appropriate category and further discussion of each theme was supported by specific participant quotes.

3.10.1.2. Description of each thematic code.

The information below should provide more detail regarding the decision making process taken in separating various themes and drawing out specific facilitators, barriers, recommendations, and quality of care improvement.

3.10.1.2.1. Early signs.

The first theme is “Early Signs.” Anything that the participant mentioned leading up to one of the three specialized eating disorder services (hospital, outpatient program, or adolescent eating disorder service) was considered appropriate for this theme. This could include thoughts about disordered eating as a young child, issues at school, and so forth. The deciding factor in what to include was how the event was related to the participant’s journey. If the participant felt that the event influenced the manifestation of mental issues or if they felt it was important then it was included. An example of an early sign was how *Phil* noticed his child was rapidly losing weight.

3.10.1.2.2. Entering the system and returns/exits.

The next theme was “Entering the System.” The main factor used to place an event in this category was whether the young participant accessed the adolescent eating disorder service, the outpatient program, or the hospital for eating issues. This was usually the point where a formal eating disorder diagnosis was acquired. However, these youth may have received some eating disorder care from another health care provider. But, the “system” in this study is considered to be a specialized eating disorder service. The events under this theme are the initial contact with the organizations; the follow-ups with these organizations would fall under the following theme of “Returns/Exits.” This return/exit may also include second or third hospitalizations, accessing additional private health care, stopping treatment, dropping out or being kicked out of a program, and any other contact with health services after entering the system.

3.10.1.2.3. Participant perceived issues.

There was much variation in this theme. Some examples of things mentioned that fit the criteria for this theme was barriers to the adolescent eating disorder service, poor school support, specific healthcare relationship challenges, or any other negative experiences related to access.

3.10.1.2.4. Positive notes.

Looking at the opposite theme of “Positive Notes”, there was a similar level of variation as “Participant Perceived Issues.” Events that the participant expressed with gratitude, and positive emotions were included, along with helpful experiences in the system, and healthcare champions. Among the most common positive notes were events that participants mentioned were when they were provided with practical resources and support for them to manage. There were several instances where participants echoed similar experiences with certain programs and organizations, both looking at facilitators and barriers.

3.10.1.2.5. School/community activity.

Any margin note, which had the word school in it, or was referring to the education system at some degree, was included under this theme. There were also various community activities such as synchronized swimming and dancing which also fell under this category. In this theme, there were recommendations, stories of fantastic school involvement and accommodation, and also stories where the education system let participants down, and fueled their mental illness.

3.10.1.2.6. Recommendations.

This theme was fairly straightforward, including anything a participant said would be beneficial in the future, or that they wish they had in their journey, or things they mentioned as a part of what they would consider to be a perfect journey. These recommendations were not segregated any further.

3.10.1.2.7. Part of the story.

This last theme came as an after the fact to the other themes. There were not many codes found under this theme. However, codes were placed in the “Part of the story” theme if they were important to the overall voice of the narrative but could not be appropriately placed under another theme.

3.10.1.3. Narrative synthesis.

After transcript revising and chronological and thematic coding, the construction of the participant’s narrative was simpler as there was a good understanding of the journey as a whole. The thematic coding document was used as a main template for each participant narrative, with reference to the participant’s transcript for quotations, and more details for each margin summary. The narrative was constructed as a chronology of the participant’s eating disorder journey as the core focus. Decisions made when creating each narrative focused on if the

participant described an event at length, and if the event was deemed imperative to gaining a true understanding of the participant journey. This included items that came up multiple times in the interview as well, along with parts of the story that the participant felt very passionate about, such as care from certain providers.

The length of transcripts was directly correlated to length of their chronological and thematic coding documents, and thus influenced the narrative write up. These documents were created and initially placed in the thesis, but have since been removed in order to protect the identity of the participants. There is a fine line between providing your participants voice, and protecting their identity, and it was deemed more appropriate to ensure the participants anonymity over detailing their full story. This being said, each participant's story has been summarized in a non-identifiable fashion in the findings chapter.

The individual participant facilitators, barriers, and recommendations tables were mainly derived from the information in the thematic coding document. The theme of positive notes was used for the facilitators, the theme of participant perceived issues was used for the barriers, and the theme of recommendations was used for the recommendations. Although the majority of these various points for each table could be found under these specific themes, a review of other notes/themes occurred, and a decision was made as to which other themes/points would appropriately fit in these tables for each participant. The grouping of facilitators, and barriers was further categorized according to whether the facilitator or barrier occurred at/from the family physician, the adolescent eating disorder service providers, the outpatient program, the family, an urban hospital, a rural hospital, school, out of province residential treatment centre or from the eating disorder advocacy organization. This was different for each participant, however all of these categories were appropriate for one participant or another. After these final groupings were

made, the tables were filled out and each table cell text was simplified into the essence of the note to avoid unnecessary details, while still keeping parts of the note that were essential to its understanding. These tables were reviewed to ensure that all information was directly related to accessing appropriate health care, whether that was as a barrier, facilitator or recommendation. The entire narrative was reviewed for errors and inconsistencies, which were then remedied.

3.11. Summary of Methodology and Methods

This research question being addressed in this thesis is: ***What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?*** Through using the ascribed method of one on one interviews with youth and parents this question could be appropriately answered. By guiding these interviews the researcher was able to allow participants to tell their story while directing them to discuss their experiences in access and care to eating disorder services. The method in analyzing these participant interviews such as illustrated in Figure 2 and 3 allowed for a comprehensive and thorough examination of each participant's story. This process forced the researcher to review participant transcripts several times for individual analysis and narrative synthesis, and then again when analyzing all participant data to create the overarching themes. This rigorous process allowed for myself to approach each participant's story in a similar manner, and to ensure that each participant's data received plenty of time and energy for analysis and interpretation. Along with this process, there was much thought and care put in to ensuring that all participants' anonymity and confidentiality was protected. When deciding whether to include certain data in the findings there was always a reflection back to whether it might identify the participant, and it was always excluded if it threatened participant anonymity.

The following Findings chapter is divided into three sections in order to guide the reader through important information in an appropriate order. The first section describes the participant's demographic information, which allows the reader to gain a better understanding of the sample. The next section explores a summary of the narratives, which allows the reader to understand each participant's story, along with the general similarities and differences amongst them. The last section is the thematic analysis of the participant journeys. This section explores the recurring, and important findings when looking across the participant stories. These themes are appropriately situated to answer the thesis research question and guiding questions regarding access to and care in youth eating disorder services.

Chapter 4: Findings

This chapter is divided into three sections: Participant Demographics, Summary of Narratives, and Thematic Analysis of the Participant Journeys. Presenting the participant demographics first provides the reader an initial context and understanding of the sample as gathered on the “face sheet” demographic survey; gender, education level, diagnosis, what the family situation was, and so on. After this, a summary of the participant narratives provides insight into the youth and parent journeys including struggles to accessing services and if/where champions existed in the system. Finally, with the demographic information and narratives summaries explored, the reader is better positioned to understand the main themes extracted from the journeys.

The demographic information section is further divided into youth participant, and parent participant groupings. There are several similarities between the youth and parent face sheets (see Appendix B and F) such as what languages were spoken at home, and what racial or cultural group the participant was located in. However, there were also some differences as well, such as asking the parent cohort how much income their family household falls under, and how many of their children experienced mental health challenges. There are two demographic summaries provided, one for the youth cohort and one for the parent cohort. There were a total of five youth participants, and six parent participants who took part in the study, and all participants filled out the demographic questionnaires. Various specific demographic information that could possibly identify participants has not been included in this thesis.

The following section includes a summary of the participant narratives. The highlights of the participant journeys are summarized in this section. Full participant narratives have been constructed and were originally included in an Appendix but were later removed in order to

further protect the participants' identities, as it was potentially possible to recognize the participants from reading their full story. These narratives have been constructed through a rigorous process defined in the Methodology chapter. Due to the large amount of detailed information collected from each participant it was not possible to include all of their recommendations, barriers, and facilitators in their narrative. There was an exploration of each participant's specific recommendations, barriers, and facilitators, however it cannot be included in this thesis in order to protect the participant's anonymity. The main facilitators, barriers, and recommendations articulated by the participants have been included in their individual narratives, with their individual narrative highlights communicated in the overall narrative summary which has been included in this thesis. These main themes have been analyzed and are presented in the following section labelled Thematic Analysis. Further interpretation can be found in Discussion and Recommendations.

The final section focuses on major themes discovered through analyzing all of the participant interviews. These major themes are categorized as either facilitators or barriers. There have been several sub-themes discovered, however the three main categories in which these sub-themes fall under are either: Initially Accessing Care, Factors Affecting Care, or Facilitators to Improved Health.

In this chapter, there are answers to the research questions we have used to frame the study. The main research question is: ***What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?*** Through the narrative synthesis and thematic analysis process, there have been several barriers and facilitators identified regarding access to and care in eating disorder treatment in Atlantic Canada, some of which acted in paradox. For example the family physician was, at times, viewed as a major facilitator to youth

receiving care, and at other times was a major barrier to their care. These barriers/facilitators range in a variety of ecological contexts, from individual to macrosystem factors. The main barriers discovered were a lack of support and services, a lack of eating disorder knowledge from primary care providers, a lack of resources including human resources, a lack of appropriate psychological support, a lack of public coverage, poor patient-provider relationships and quality of care provided, waiting times, timing and location of programs, and a lack of motivation to change. The major facilitators identified were knowledgeable primary care providers, appropriate and available psychological services, the eating disorder advocacy organization, the outpatient program, a motivation to change, the adolescent eating disorder services, parental education and support groups, and parental advocacy. There were also discoveries related to the guiding questions as well.

What health services are these patient populations currently accessing? All youth and parent participants spoke of accessing a primary care provider. The majority mentioned access to a psychologist, to the adolescent eating disorder service and/or the eating disorder outpatient program. Many participants accessed services through the eating disorder advocacy organization, and also many participants accessed services through the hospital such as the pediatric psychiatry unit and internal medicine unit. A few participants alluded to accessing services through the emergency department, and a single participant also accessed services through an adolescent day program. One participant had accessed an out of province residential treatment centre. Participants mentioned speaking with guidance counselors in the school environment as well.

In knowing this information, the question: ***What services are they accessing through other agencies (e.g., education, social work, private sector providers?*** can be more fully interpreted. The main finding was that many participants had to access psychological support through the

private sector, and several participants also spoke to a guidance counsellor in the education setting.

There is need for a more thorough exploration in answering the guiding question of *What services are effective/ineffective and why?* which is touched on in the following chapter, Discussion and Recommendations. This was only a brief discussion of how the findings inform the research questions, as there is an in-depth discussion in the following chapter.

4.1. Demographic Information

4.1.1. Youth Sample.

All five youth participants shared certain demographic characteristics. They all viewed their families as having “enough money” and had received a diagnosis of having an eating disorder from a health care provider. The gender of the youth participants was collected but shall not be disclosed in order to further protect their identity. Although the gender of participants may impact certain eating disorder behaviours it is not pertinent to the current research study. In addition to having an eating disorder diagnosis, some of the youth had co-morbidities.

All youth participants accessed at least one specialized service including inpatient hospitalization, day program and outpatient services. Outside of these services, youth participants also accessed services from their family physician, private psychological counselling, and from a guidance counsellor. In order to protect the identity of participants, some of the demographic information has been scrambled in the composition of the participant narratives, and other findings. This includes scrambling their age, gender, and name, to ensure their anonymity.

4.1.2. Parent Sample.

Similar to the youth cohort, the six parents shared many of the same responses in their face sheet answers, such as being fully employed. Three of the six parents interviewed were dyads, meaning their children were also interviewed for this study. The genders of the parents will not be reported to further protect their identity. The parent sample ranged in terms of their educational background.

All six parent participants had a child with a formal eating disorder diagnosis, with some of the participants mentioning their child had co-morbidities as well. Five of the participants had paid for their child's mental health services at some point, which ranged from a few hundred dollars up to several thousand. When asked if they would be willing to pay for better, and/or faster services for their child, four of the participants said they would, with two saying they would not. When further probed, the participants provided a variety of explanations to support their choice. One of the participants mentioned that they did not morally believe that access to services should be based on willingness to pay; this should be equal for everybody regardless of socio-economic status. Two of the participants echoed similar thoughts in that if the service was available and faster, they would pay for this. Another two of the participants said if services were better or good then they would be willing to pay. One of the participants said services are already expensive such as psychological counselling, which costs \$150/hour, and that they have already used up their private insurance. When asked how much they would be willing to pay for services, only two participants responded. One suggested they would pay whatever was required for both faster and/or better services, and the other participant said they would pay 20% more for faster services, and 50% more for better services.

All of the parent participant's children had accessed at least one specialized service including inpatient hospitalization, day program and outpatient services. These were comparable to the findings from the youth sample. Similarly to the youth participants a variety of the parent participant's demographic information has been scrambled in order to protect the identity of participants. This includes changing their age, gender, and name.

4.2. Narrative Summaries

In order to more fully relate to each participant's journey, a full narrative for each participant was developed from his or her interview transcript. This process ensured that the participants lived experiences were not fractured but were constructed to allow the comprehensive story to emerge. These narratives were derived from the participant transcripts, which ranged from ten to 33 pages, being linked to how long each interview was, which was largely influenced by how much each participant had to say. This section provides an overview of the joys, challenges, and struggles arising in the participant narratives and that are directly relevant to the research question of exploring the barriers and facilitators to access and care. The details of these journeys are of utmost importance to understanding the findings beyond a surface level. The full narratives were used to create these narrative summaries.

Deciding what parts of the narratives and journeys were to be included and excluded in this section was determined through reflecting back to the main research question. Some choices made involved an exclusion of how the school factored into youth journeys. School was a major part of the journey for some participants, but it did not act as a direct barrier or a facilitator to accessing care and is therefore not discussed here. Similarly, the subject of resources, such as a lack of appropriate food, is not discussed here even though it is an important area and is detailed

in other parts of the thesis. This section highlights youth and family journeys in relation to access to services. Structural issues in the system and recommendations follow later in the thesis.

All 11 participant journeys are briefly described in this section. There has been a wide range of experiences in accessing services, and participants not only ranged in demographic information, but in stages of eating disorder development and recovery. Some participants had only recently accessed eating disorder services and were still navigating their way through the system, while others had been several years exploring services, and had even accessed treatment outside of the province. Participants articulated using similar services, such as the outpatient program, the pediatric psychiatry unit, and the adolescent eating disorder service, and also participants used different providers for care, such as private psychologists, out of province residential treatment, and differing forms of therapy.

When exploring the early signs, participants had vastly differing childhood experiences, with some being involved in sports, and music, and others were more interested in writing and working. These youth were positioned in varying life stages, social spheres, and levels of education, which provided differing angles to exploring their journey. Participants also ranged in their introspection of having an eating disorder or recognizing that something was “not right.” When exploring the perspective of youth, and then the parents there were some areas of unity and some areas of divergence. This multi-vocal perspective provides for a unique exploration and interpretation of the findings.

Through this narrative analysis, the experiences of these youth and their families can be appreciated in view of their environment, and motivations from their own voice, in a way that is not possible through thematic analysis alone. Looking across participants there were nuances in each story, and paradoxical situations that can only be appreciated with knowledge of participant

circumstance and context. For example, *Carl* (youth) and *Laura* (youth) both accessed the outpatient program but had vastly differing views on access and care provided. One graduated from the program and the other left saying “I’m never coming back here [the outpatient program] again.” Through the participant narratives, we can see how journeys are the same and different while living in different realities in accessing eating disorder services.

The first narrative summaries are from *Rachel* and *Carl*. *Rachel* was a pre-teen when she first forced herself to throw up. Following this, she became obsessed with exercising, her weight, and bingeing and purging. *Rachel* had her first appointments with a family physician and a private psychologist after this point. These appointments were not helpful for *Rachel*, who then attempted to access the outpatient day program. After a rigorous interview process, she was denied entry into the program, which upset her. After this *Rachel* continued to visit her family doctor’s office for help, where she “never received any.” A short while later, she went to the hospital for a check up and was admitted to the pediatric internal medicine ward after staff discovered her heart rate and weight were quite low. While admitted, *Rachel* was tube fed, put on the eating disorder protocol, and forced to consume “about 5000 calories a day, which was crazy.” She really did not want to be in the hospital and felt the staff were mean and were “trying to make me fat.” *Rachel* said the constant visits by her friends made the process easier, and that some of the staff were kind and compassionate while others were condescending and intrusive. Near the end of this hospitalization period, *Rachel* enjoyed taking part in the art therapy sessions. After discharge, *Rachel* was determined to stay out of hospital and said it was “really bad” and “really hard” the first few months but it eventually got better. She started monthly check ups as an outpatient in the adolescent eating disorder service, which occurred for several months, and

the staff commended her motivation for recovery. *Rachel* was released from outpatient care and says this “is really good, [because] they usually follow up for several years.”

When *Carl* was a preteen he remembers one of his coaches telling him not to eat junk food before a competition, a message that he took to the extreme and cut out all junk food for years. He remembers always being worried about food and would compensate for eating with excessive exercising, in the name of being “healthy.” After high school, *Carl* moved in order to pursue school, where his lifestyle changed drastically to a “lot of drinking” and “smoking pot.” After an abusive relationship ended, *Carl* felt disgusted with himself and just wanted to melt away; thinking losing weight would be a great way to do this. *Carl* did not eat over 300 calories a day for the entire semester and soon started to realize this was not “normal.” He wanted guidance to help him get back to regular eating but did not receive this support when he visited his family physician. The disordered eating continued until *Carl* collapsed one night and was completely disoriented. *Carl*’s parents encouraged him to seek help through the hospital. At the hospital, *Carl* was admitted to the internal medicine unit to be stabilized. He was transferred to the psychiatric unit after this, and felt that the care was not very good. After a couple of weeks *Carl* was discharged, and was set on transitioning to the eating disorder outpatient program. *Carl* was initially denied access to the program because his Body Mass Index (BMI) was too low. *Carl* called the outpatient program several times saying he needed help but felt brushed off by the staff, “I was told *no* we’re not having another orientation for three months because this person’s going on holidays, and this person’s doing that and stuff.” *Carl* relapsed while home, and was admitted to the hospital following a referral from a new family physician. This family physician was very kind, and *Carl* says he would not be alive today without this physician’s support. This hospital was different than the first one he was admitted to in that it used a developed eating

disorder protocol. He did not care for the majority of the staff and felt they lacked compassion in their care. While still in hospital *Carl* slowly integrated into the outpatient program. He attended the program full time after he was discharged from hospital, but had major issues with the staff who told him he did not belong in the program, and that he was not trying to get better. He was also seeing an individual counsellor at the time, but felt she did not attend to the eating disorder issue. *Carl* continued to lose weight, and was eventually told to go home from the outpatient program until he had gained more weight, to which he responded, “I’m never coming back here again.” *Carl* has gone back to school, and has tried to connect with some other services. Unfortunately *Carl* has had a difficult time connecting with providers, and currently feels “lost”, “scared”, and “out of options.”

The next six narrative journey summaries are those from the three youth and three parents who are familial dyads. We have defined a dyad as the grouping of a youth participant and their parent as a participant. These groupings provide the vocalized narratives from *Amir* and his mother *Hilda*, *Laura* and her mother *Yvonne*, and *Tom* and his father *Phil*. These narrative summaries comprise a multi-vocal melding between youth and parent. There is therefore a further level of analysis for these separate and sometimes interwoven voices (further data is provided in the Multiple Voices section).

Amir’s journey begins when he started exercising excessively, weighing himself constantly, and making elaborate meals but not eating any of them. During a family vacation, *Amir* found it difficult because he could not exercise, and he forced himself to throw up a couple of times. At this point he started to realize something was wrong, “I didn’t know I had an eating disorder, but I knew what I was doing wasn’t normal, and I had to hide it so I was kind of freaking out, and I think they [parents] started to really notice around then.” His parents had

spoken to him a couple of times regarding his changes in behaviour, but shortly after this trip his parents said “We’re concerned about your health, we’ve been noticing these behaviours and they’re very concerning to us, and we’re going to bring you in to see the doctor about it.” *Hilda* (mother) recalls *Amir* being extremely relieved as he was hoping someone would notice. There was a connection made with their family physician who was “very helpful” and referred *Amir* to an adolescent eating disorder service right away. While waiting for his appointment to the clinic, the family decided to connect with a private counsellor for some guidance and immediate support. Both *Amir* and *Hilda* recall this psychologist being “more harmful than helpful”, in that the counsellor told the parents not to tell *Amir* he had an eating disorder as this would be labelling him for life, and that they were to blame for the development of this eating disorder. The family stopped these sessions shortly after. *Hilda* also mentions that psychological services should be publicly funded and covered, as “it’s basic healthcare.” At *Amir*’s first session with the adolescent eating disorder services, *Hilda* explained how there was a “wonderful multidisciplinary approach that was taken right from the first visit. We saw a nurse practitioner, we saw a general practitioner, we saw a dietician, we saw a psychologist, and we saw a social worker. I was so impressed by, and this was on our first visit. Very first time we went in there.” *Amir* and *Hilda* had only positive remarks about their care at the clinic, stating it was a “great experience”, and that the psychologist was “the biggest part.” *Amir* has accessed services at the program for several years and still has access to services if needed. In terms of the eating disorder, he is in recovery.

Laura recalls not eating supper if she wanted to wear a certain outfit to school the next day. It was something that she started doing and no one noticed, so she continued and the restricting grew continually worse. She would work full days without eating or taking her break, and would

start to feel weak. One night she arrived home from work, and felt nauseous because her body was so hungry, and she mentioned to her mother (*Yvonne*) who recalls her saying “I think I might have an eating disorder, and before it gets any worse I want to do something about it.” After meeting with her family physician, *Laura* saw two separate psychologists, as the first one had been “overwhelming.” Both *Laura* and *Yvonne* felt their family physician was knowledgeable about the appropriate steps and services for her, and eventually *Laura* was referred to the outpatient program. When she first accessed the program she did not enjoy the program and was “terrified” to go there. She eventually connected with other people there and started to find the program very helpful. After four months of attending the program nearly every day, she eventually scaled back her time at the Centre. *Yvonne* says, “[the outpatient program] was phenomenal” and “everything about it [the outpatient program] was really helpful.” She mentions that the psychologist at the program was really good and was “the biggest step in resolving or getting her [*Laura*] to the point that she’s at now,” a positive statement with which *Laura* agreed. *Laura* graduated from the program and mentions that she is recovered from her eating disorder but still accesses psychological support from the program because the therapist is “the best one I’ve been to.” *Yvonne* also mentioned how “phenomenal” *Laura* was in her motivation to get better and that she was the driving force to accessing services and to reaching her current state.

Tom had “got into his eating disorder” during the fall when he was losing a lot of weight and “was getting really sick, or I thought I was getting really great.” His father (*Phil*) was always urging him to gain weight and get healthier, but soon after became concerned with *Tom*’s rapid loss of weight, and behaviour changes. They went to see their family doctor on several separate occasions because *Phil* was becoming progressively more concerned about *Tom*’s health. But,

the family physician kept brushing his concerns away claiming that *Tom* did not have an eating disorder, and that he had been a larger child and losing the weight was healthy. *Phil* made contact with the eating disorder advocacy group, who provided him with a referral form for the outpatient Centre. On their last visit to the family physician *Phil* brought the form along, and to the dismay of the physician *Tom* was under the criteria for admission, but the family physician sent the form to the outpatient Centre anyway. Two months elapsed after which a health care provider contacted *Phil* and told him that according to *Tom*'s form he was quite sick and needed to be brought into the hospital immediately. *Tom* was admitted to the pediatric psychiatry unit, and he was "furious with everybody." Throughout this hospitalization period he started warming up to the staff and enjoyed the art therapy sessions that were offered. After his discharge he continued with check ups at the hospital, and started in the outpatient program. At first he had reservations about the program, and felt he did not belong there or anywhere. After a discussion with *Phil* and his care coordinator, he decided to continued with the program. He eventually made some friends and started to find the different group sessions helpful. *Tom* has graduated from the outpatient program. He stated that this program was the "biggest help" for him. "I think the [outpatient program] has definitely been like the biggest help" and "it gave me a whole new perspective on my life, and that was definitely the greatest thing." *Phil* also believes that there was a turning point when they went on a family vacation, as he saw *Tom* break away from some of the rigidity of his meal plan and showed a newfound self-confidence. *Phil* said following this trip, *Tom* became consistently better and he cut back the frequency of his check ups with the clinic to monthly. *Phil* also found the parent support groups offered through the eating disorder advocacy group to be extremely helpful for his own journey, providing a place for support and education.

The final three narrative summaries come from three parent participants *Veronica*, *Frank*, and *Rosie*. *Veronica*'s daughter had always been very active and outgoing. *Veronica* had no concerns about her child and never suspected she may have a mental health issue. Looking back, she said that her child "had started to slim down in weight", but she thought this weight loss was normal because of her child's age and involvement in sports. *Veronica*'s child mentioned she had not had her period for a couple of months, and this concerned *Veronica* who set up an appointment with their family physician. This physician recognized her child's symptoms and set up an appointment with the adolescent eating disorder service. While waiting for this appointment *Veronica* mentioned that it was then that her daughter told her "Mom, I'm anorexic." From that point, *Veronica* said they were in "a terrible place, a horrid spot" for the rest of the waiting period. She was trying to get her daughter into the clinic faster, but they were incredibly busy. She said her child had stopped eating entirely at this point and was admitted to the pediatric psychiatry ward upon this initial appointment. There were few patients in this unit at the time and *Veronica* felt that staff were compassionate, but did not provide much instruction. After a few months of hospitalization her child was discharged, and started weekly check ups with the adolescent eating disorder service. *Veronica* located and paid for private psychology sessions for her child. For the following year her child was doing well but then became ill again and *Veronica* begged the hospital to have her admitted. After a wait, *Veronica*'s child was admitted to the pediatric psychiatry ward, and was soon after transferred to the internal medicine ward to accommodate for another child. This hospitalization period ended with her child slowly integrating into the outpatient program. This was two-days a week, and her child felt stressed about missing so much class time, although she found the program "very beneficial." After four months of utilizing services at this outpatient program *Veronica*'s child went away for a few

months. This was a major turning point in the journey. Things have been “completely different” since her child returned, and *Veronica* was happy to say that currently “It’s almost like an eating disorder doesn’t exist in our home.” Her child has stopped accessing the outpatient program services, and continues to see her psychologist, and the adolescent eating disorder clinic, however at present time *Veronica* says her child is “doing marvellous.” She notes, “I really do believe that the psychologist she was seeing was huge, was major, in helping her get through that.”

Frank recalls his child starting his first diet after moving to a new school. He soon after started restricting food, as encouraged by a sports coach, and started experimenting with drugs as well. As the year went on, his child obsessed over food and exercised excessively, which prompted several visits to the family doctor, who discussed the idea of healthy eating. The family physician could not refer his child on to the adolescent eating disorder service until his vital signs were below a certain criteria threshold. Thus for a period, the child and his family tried a variety of counselling options. After this year of waiting, *Frank’s* child became quite ill and finally received his referral and initial appointment to the adolescent eating disorder service from their family physician. This appointment occurred two weeks after the initial referral, and the teenager was diagnosed and admitted to the internal medicine ward the same day. After he had been stabilized, he was transferred to the pediatric psychiatry unit where he would spend the next two months. *Frank* felt there were some issues with staffing and that “I don’t feel that it [they] was diligent enough.” After his child’s hospital discharge, the family attended family therapy sessions, sessions with a hospital social worker, and obtained support from a private psychologist as none were available through the hospital. *Frank’s* child was readmitted to the hospital several more times, and they had to request to have him put on the eating disorder

protocol on many of these occasions. Nearing the end of one of the admissions his son was slowly integrated into the outpatient program. Although his child was initially doing well at the outpatient centre, “they asked him to leave [the program] basically until he got the drug problem under control, [and] that he wasn’t getting anything out of it.” *Frank’s* child eventually started attending an adolescent day program but had to leave this program as well due to his substance abuse issues. Upon recommendation of the pediatric psychiatrist, *Frank* and his son left the province to seek care at an out-of-province treatment centre for a few months. *Frank* felt this experience was beneficial for his child, but was very upset with not receiving the funding he was promised from the Medical Transportation Program for accompanying his son during this treatment. After returning from the program there were still no psychologists at the adolescent eating disorder service, thus his child started attending the adolescent day program again. His child became heavily involved in drugs again, and moved out of *Frank’s* house. He had checked himself into a recovery program, and moved back into the house for a few months until the end of the school year. He has moved out again, and has had his last pediatric appointment; he has now been discharged from the youth health system. Currently, *Frank’s* son is on an 18-month waiting list to see an adult psychiatrist, and he has been removed from the adolescent program again. *Frank* says “[we are] at the stage now [where] I’m expecting a call any day, [saying] he’s fainted” and now his son will have to try to access services in the adult system. *Frank* has said overall that the adolescent day program gave them “the most beneficial practical help”, and they went out of their way to be accessible, and to educate themselves on eating disorder care.

Rosie had no idea that her teenage child had an eating disorder. A school guidance counsellor called *Rosie* and explained that she believed her child was having some eating issues. From this point, *Rosie* set up an appointment with their family physician who made a referral for

the adolescent eating disorder service right away, an act which *Rosie* commended. It took about a month for her child to have this initial appointment at the clinic after the referral was made. *Rosie* mentioned that their wait time for the adolescent eating disorder service was not too long, but she did say, “When you discover that your kid has a serious problem you really want it to be attended to kind of urgently.” At the initial adolescent eating disorder service appointment the whole team met her child: physician, social worker, and dietician. There was good follow-up with the adolescent clinic, and they were “very good.” The team did not have a psychologist, and after months of searching, and a very “frustrating” process *Rosie* located an appropriate private psychologist for her child. The parents took part in the 8-week informational/educational program from the eating disorder advocacy organization, claiming it was very helpful with “lifesaving sessions.” *Rosie*’s child had a stressful, and “rocky transition” into school, and shortly after was admitted to the pediatric psychiatric unit for issues unrelated to the eating disorder. After this three-week period her child was discharged from the pediatric psychiatry unit but her eating disorder started to ramp up again. At this point, the family was taking part in family counselling with a hospital social worker. The outpatient program had also been in contact with *Rosie* and her child about coming in for an interview. After much deliberation about attending the outpatient program, they were forced to cancel this appointment because her child was admitted to the hospital. *Rosie* feels slightly apprehensive about her child entering the outpatient program with individuals who are much older and “more experienced in the world of eating disorders”, thinking it could be a place where she would further develop her eating disorder. During one family holiday *Rosie* was in and out of the hospital with her child everyday looking for support and guidance. Her child was continuing not to eat and *Rosie* felt at a loss. Eventually, after a “stressful, horrible and frustrating” time between seeing multiple different

health providers, *Rosie's* child was readmitted to the pediatric psychiatry ward. *Rosie* had connected with a counsellor for herself but did not find this helpful, and thinks speaking to someone who provides direct psychological care for her child may be helpful. *Rosie* feels the situation is becoming increasingly more complicated, and that she needs help.

These narrative summaries bring light to the differences and similarities in youth accessing services related to treatment for their eating disorders. They provide a flavour for the context in which we can interpret the thematic analysis, and how each discovery is not simply a fractured point but is embedded in complexity across school, family, peer, health care, and community environments. Access is to be understood as a systemic issue as much as an individual issue. Suggesting increased resources/capacity or a change in program criteria without knowledge of the overall picture is not only ineffective but also inappropriate. These narratives provide a human voice for readers to hear and to more easily comprehend how youth and families with eating disorders in Atlantic Canada attempt to access health services. These narratives provide answers to the overarching research question of the study, while holding value for enhanced policy planning, and program reorganization.

4.3. Thematic Analysis

When analyzing all 11 interviews together in a thematic rather than narrative sense, several recurring themes arose. I have first presented a composite of participant barriers and facilitators in two tables. Following this, the themes have been categorized into different levels. The prevalence of each of these themes varied, with some being mentioned at length in most interviews (e.g. the role of the family physician), while others were mentioned in a couple of interviews (e.g. turning points). All of the themes in this section have been articulated by at least two of the participants, with most of them being mentioned in all narratives. Each theme is

discussed in detail, with reference to how prevalent it was and with direct quotes from participants to provide context. In order to increase readability of this section only one or two participant quotations are used although there were several relevant quotations for each theme. It is worth recalling from the Methods Section that a composite list of themes was developed through revision of participant chronological and thematic coding documents, narratives, and facilitator, barriers and recommendation tables (see Appendix S and Figure 2). The list of themes is linked to quotations and organized into three categories; Initially Accessing Care, Factors Affecting Care, and Facilitators to Improved Health (see Figure 3).

4.3.1. Composite Barriers And Facilitators.

Similar to the narrative summary, this section provides a consolidation of the composite participant voice in a more concise view of what worked for participants and what they were still facing as barriers to access and care. The tables for each participant's specific barriers and facilitators to access and care, along with the composite themes (Appendix S) provide the raw data for these summary composite tables. There were decisions made regarding what to include/exclude in these tables. This decision making process was similar to the process for the narrative summaries, in that all responses were evaluated in the context of the research question about barriers and facilitators to access to and care. Included were themes that participants mentioned directly. Excluded were themes that did not directly impact the participant's access to service or care, such as certain school experiences.

Many of the participants shared common barriers and facilitators, while some articulated unique findings. Of interest is how many of the recurring themes acted in paradox. Take for example the family physician, who for three participants (two parent, one youth) acted as a major barrier to accessing services. But, the family physician acted as a main facilitator to care for four

other participants (two parents, two youth). One youth had paradoxical experiences with two separate family physicians where one was “infuriating” and the other was “the only reason I’m alive.” Items that have been described paradoxically have a (p) listed to illustrate this paradoxical placement in the tables.

The tables are arranged in order of barrier/facilitator importance in accordance with participant responses and researcher interpretation. The most important barriers/facilitators are at the top of the table, which in *Table 1* would be an eating disorder advocacy organization, and in *Table 2* would be psychological services. It must be noted that participants were recruited for this study with the help of an eating disorder advocacy organization. The second most important barrier/facilitator is the family physician/adolescent eating disorder service following after this, and so on.

Table 1. Facilitators to Access and Care from Participant Interviews

Eating disorder advocacy organization- Parents support and educational group, and Emotion focused family therapy
Adolescent eating disorder service
Outpatient program (p)- Psychologist (p), and Making friends through services
Family physician (p)
Parental advocacy
Compassion/empathy in care and “good” providers
Art, music and writing therapy
Family support
Multidisciplinary approach
Dietician
Psychiatry unit (p)
Individualized care
Willingness/motivation to get better and self-recognition of an issue
Internet

Table 2. Barriers to Access and Care from Participant Interviews

Psychological services (p)- Accessibility, and Lack of public coverage
Family physician (p)- Lack of eating disorder knowledge, and Not taking concerns seriously
Lack of staff and family education- making insensitive comments
“Bad” health care providers- A lack of empathy, and not acting professionally
Hospital- Internal medicine unit, Psychiatry unit (p), and Emergency unit
Lack of resources/capacity- Waiting period of places in hospital ward, and Lack of “appropriate” food in hospital
Lack of coordination/communication- Amongst different service providers, and Transitions
A lack of awareness- Eating disorder symptomology, and Services available
Program/clinic timing-During work/school hours
Stigma
Outpatient program (p)
Geographical location- All specialized services only available in the capital city

4.3.2. Initially Accessing Care.

4.3.2.1. *Family physician.*

The role of the family physician was mentioned in every interview. This role varied depending on the participant’s experience, which placed the family physician as a facilitator or as a barrier to accessing specialized eating disorder care. In all of the interviews, the family physician was mentioned at the very beginning of each journey as “a first point of contact.” These physicians act as a gateway to specialized eating disorder services. Also, when asked

about an ideal journey the majority of participants pointed to the family physician to be the first point of contact, and the person who directs the care pathway. Through speaking with participants, it is clear that the family physician is the first step, and an instrumental player in directing patients to appropriate care. In exploring whether the participant was able to access appropriate next level services, the family physician's education and awareness relating to eating disorder care was of high importance. There was no mention of a barrier to accessing the participants' family physician, as this process seemed to be straightforward. In the majority of cases the family physician was not connected to the participant's journey after they had accessed more specialized eating disorder services. They may have still seen the patient for other matters, but they would not ask questions regarding the participant's activities connected to their eating disorder care. To the participants' knowledge there was not much, or any communication from their family physician with the other eating disorder care providers.

There were several examples where family physicians were strong advocates for their patients' needs, and where they enabled quick access to appropriate services. For six of the participants (two of the dyads) their family physicians were well aware of how to manage their care, and referred them onto a psychologist, the outpatient program, or the adolescent eating disorder service. These participants noted their family physicians were "exceptional", "knew exactly what to do", "immediately started asking questions", and quickly touched base with essential specialized providers. In many of the cases, the physician might not have been highly educated on eating disorder care, however they all knew who to contact next, and whom the participant should see next to receive necessary advice and care. In some of these instances, the participant would be referred to a psychologist first prior to making a connection to the outpatient program, or the adolescent eating disorder service. All of these participants did

eventually make that connection with either the outpatient program, and/or the adolescent eating disorder service.

The other five participants (one dyad) spoke about their experience with their family physicians as a barrier to receiving eating disorder care. Youth echoed similar experiences with their family physician in that they did not receive specialized eating disorder care until they themselves went to the hospital and were admitted. Other participants had to wait a lengthy period before their family physician would refer them on to more specialized services. All of these participants believed that there was an eating issue, and were looking toward their family physician for further help. However, their family physicians acted as a barrier to receiving this care, either due to a lack of education surrounding eating disorders, or certain restrictions to perceived referral policies. One participant noted that their “family physician was the biggest barrier to care.”

A point made by many participants was that their family physician did not provide practical advice or guidance regarding what to do in the interim while waiting for their referrals. These participants felt out of their element, and did not know what the next step was, or who to contact. This situation proved to be a significant stressor.

4.3.2.2. *Psychological services.*

An important service provider for eating disorder care is the clinical psychologist. In many of the interviews participants sought psychological services before accessing the outpatient program or the adolescent eating disorder service. Also, there were lengthy periods of time where the adolescent clinic has been operating without a psychologist, in which case there was a need for patients to seek out private counselling. A point consistently raised by the participants, and one that they were upset about. This topic of accessing a clinical psychologist is

multifaceted, and was discussed as a barrier by participants. Two main barriers were the inability to find a psychologist who had appropriate eating disorder experience and had capacity for a new client, and in this psychological service not being covered under public insurance.

In looking at this first barrier, only a few of the participants were fortunate to connect with an experienced private psychologist. Some common issues were that it took a lengthy period of time to locate a psychologist who had capacity for new clients, finding a psychologist trained in eating disorder care was rare, and it was difficult to find a psychologist who did not evoke feelings of anxiety and shame in participants. Some of these participants had to connect with psychologists themselves, or through their family and friend networks. Other participants received referrals from their family physicians, or through their Employee Assistance Program (EAP) from their employment. These experiences left participants with a variety of feelings, such as frustration, guilt, and being overwhelmed. For example, one dyad explained that they had a “horrible experience” with the psychologist they had seen. This psychologist was not trained in eating disorder care, and said some “quite disruptive” things to them, such as pointing to the parents as a cause for their child’s eating disorder development.

All of these participants had to pay for the psychological services through out-of-pocket or their private health insurance coverage. The average cost for an hour psychological session was estimated to be \$150 per hour. Most participants used up their psychological service coverage from their health insurance policy in only a couple of sessions. The majority of participants said that these sessions were required every two weeks, or monthly for an extended period of time, ranging from a year up to several years. As one can imagine the expenses associated with these services can add up very quickly, and as one parent mentioned, “How many people have an extra \$500 a month laying around?” While *Hilda* (parent) said that this type of psychological service

was a major factor in her child's health improvement, and it should be publicly covered as it is "basic healthcare." For some individuals this essential service cannot be accessed simply because they cannot afford it. This barrier limits individuals from attaining such care depending on their socioeconomic backgrounds.

4.3.2.3. *Waiting period.*

The waiting period between initial referral to a specialized service can be a very difficult time for families, as was the case for several participants in the current study. There was a difference in waiting periods amongst participants in both accessing the adolescent eating disorder service, and the outpatient program. For the adolescent eating disorder service the waiting period ranged from two to six weeks, while the outpatient program ranged from three to eight weeks. Some participants also had to wait to be hospitalized.

A message echoed by several participants is summarized by *Hilda* (parent) who said "When you're dealing with an eating disorder, a month or two can make a huge difference, and you're just living with this condition." In addition to *Hilda*, several of the other participants also had to wait several weeks before they could access the adolescent eating disorder service. Many of these participants realized afterward how busy the clinic was, and that a six-week wait was about the average time.

Looking at waiting periods for the outpatient program there were three barriers that were commonly discussed. These involved having a three-week interview process, waiting for a family physician to make a referral to the program, and miscommunication between service providers and the outpatient program. Take for example one dyad, who mentioned that it took several months from when their physician sent the referral to the outpatient program for the adolescent eating disorder service to contact them regarding the outpatient program. At this point

the child was rushed to the hospital, and was admitted because his vitals on the referral form were very low given that they were actually taken two months prior.

Two of the participants also had waiting issues with receiving care and guidance from the hospital. This involved having to wait an extensive period of time for beds to be available in the pediatric psychiatry unit, and barriers in the pediatric emergency department. One parent for example brought her child to the emergency department nearly every day for weeks looking for guidance on what to do with her. The participant noted it appeared as if the various health care providers kept delaying her child's admission into hospital. Eventually her child was admitted at the end of this period, however all of this waiting and delaying of treatment was very stressful and frustrating.

The waiting period was a barrier to access for the participants, with some only having to wait a few short weeks, while others having to wait a few months. During this waiting period youth were in need of support, and families were "out at sea" not knowing how to manage their situation.

4.3.2.4. *Timing of programs and geographical location.*

The timing of programs, and the geographical location of services were two barriers to access that were voiced by some but not all of the participants. When looking at both the adolescent eating disorder service, and the outpatient program, they operated during the regular 9-5 work day. This is an issue for participants on two fronts; it is difficult to take the time to drive a child to appointments during these work hours, and also youth end up missing a substantial amount of school time. One parent summarized this issue in the interview by saying,

The timing of some of the programs, I understand that you know most things operate Monday to Friday, 9 to 5, but with this particular disorder, most of these children are

perfectionist, or a lot of them are. They're very high achievers, for them interfering with their school length on top of all the other things causes some high stress, so some kind of commitment to provide opportunities outside of those normal hours, would of been extremely beneficial.

This highlighted the various issues with the timing of programs, and how it can be a big burden for families.

A major facilitator in terms of access and quality of life for a separate parent participant (*Hilda*) was in the convenience of the parent's appointments with the adolescent eating disorder services coinciding with their child's appointments. Having a steady, stable "clinic once a month" where they would "see all these different doctors" ensured that the parents "were not constantly running back and forth to appointments."

In exploring geographical location, this barrier was different for each participant who discussed it. These barriers involved having to move to the capital city in order to receive treatment, and also having to relocate to access services outside of the province. All of the specialized eating disorder services, and support programs for families are only available in the capital city. With this being said, the parents' support group does offer a telecommunication option for parents throughout the province to call in for the sessions. In looking at this second barrier, one youth required a more intense treatment option than the outpatient program, and travelled out-of-province for treatment. This treatment period was three months long, and their parent stayed with them for this whole time as it was seen as necessary. The Medical Transportation Program had told the parent they would cover his expenses for accompanying his child, which was upwards of several thousands of dollars. However, the parent is still battling with the Medical Transportation Office to receive this promised reimbursement.

4.3.2.5. *Eating disorder advocacy organization.*

Another form of care is family support and services offered through an eating disorder advocacy organization. Initial access to this organization was straight forward, and easy. A counsellor at the association was available all the time, and “took the time to personally meet [the parent participant] (*Rosie*).” The organization was able to provide guidance and direction for parents right away in regards to their own support, and options for their child. For one parent, the counsellor allowed him to join the educational program halfway through to receive some education and support. When looking at the accessibility of this organization it was very good, and was a major facilitator for parents to receive support, and helped guide families to make decisions about their child’s care pathway.

4.3.2.6. *Knowledge.*

Another factor that had an effect on participant’s initial access to services was the knowledge they or their family physician had at the start of the journey. This knowledge was in reference to eating disorders, and eating disorder care available in the province.

Four of the youth participants recognized that there was something serious going on, and brought this forth to their parents. In recognizing they were having eating issues, they were not a barrier to their own care, and then made connections with either their family physicians or the hospital to try and get help. These participants brought forth their issues to their parents by telling them, “Mom, I’m anorexic (*Veronica*)” or “ I think I might have an eating disorder, and before it gets any worse I want to do something about it (*Yvonne*).” Without this prompting, the parents of these participants said they did not know anything was wrong or that their child needed help. This self-recognition, and willingness to seek help was a big facilitator for accessing care.

The Internet was a facilitator for participants in acquiring knowledge surrounding eating disorders and care. It provided participants an avenue to learn more about the outpatient program, and eating disorders in general. In the case of *Phil* (parent) and *Rosie* (parent), they each discovered the eating disorder advocacy group through Internet searches and were then connected to the various support, and education programs offered through this organization. One parent participant was also able to receive an outpatient program referral form from this association, which led to their child connecting with necessary eating disorder services.

4.3.3. Factors Affecting Care.

4.3.3.1. *Quality of health care provider.*

When receiving care, a major topic explored by participants was access to high quality care provided by health care workers. The quality of care ranged from a variety of considerations including providers carrying out their specified duties, providing compassionate care, acting in a professional manner, and providing guidance to the participant. The experiences participants had with providers proved to be barriers and facilitators to a positive experience with care. The services mainly utilized by participants, and discussed in this section include family physicians, clinical psychologists, hospitals, an adolescent eating disorder service, an outpatient program, and an eating disorder advocacy organization.

4.3.3.1.1. *Pediatric psychiatry unit.*

Participants had a variety of good and bad experiences when exploring quality of care during time spent in the pediatric psychiatry unit. Looking at the facilitators first, some participants found the staff really capable and compassionate, and showed respectable attention to care. These participants mentioned that the staff were easy to talk with, made them feel included, and helped make them feel good about themselves. It was said that services in the

summer months provided better staff to patient ratios, and also that the life skill building sessions were helpful. When talking about her child's experience in this unit one parent mentioned,

They were amazing. They were so, so, so, good, and he [his son] didn't like them, but they did such an amazing job, the nurses, and the doctors, and the dietician, and stuff, they did such an amazing job with explaining to him this is what you need to do.

There were also several barriers to good quality of care on the psychiatry unit. These included staff not being diligent enough in watching over patients, staff not providing parents with eating disorder information right away such as guidance on what they should be doing, and a lack of capacity and resources. One participant also mentioned that the entire family, including their child had been shown a video of some young girls who were recovering from eating disorders, and thought this was not appropriate for her child to see at the time. Also it was mentioned that staff needed to be better educated on what to avoid speaking about, as one youth recalled staff talking about weight and calories openly, two things that were triggering for some of the eating disorder patients.

In looking at resources, this included not having enough capacity on the floor, as some participants had to wait a long time for their child to be admitted, or their child had to be moved to the internal medicine unit in order to accommodate another child. Also, connected to a lack of resources, some participants mentioned that a major barrier to care was a lack of "access to appropriate, adequate and acceptable food." As one parent mentioned, this is an extremely important piece for people trying to re-nourish themselves, as they have specific foods that they can and cannot eat. Due to the lack of specific food available in the hospital one parent had brought in over 100 pounds of fruit on two separate hospital admissions for her child (and others), saying:

I'm not talking exotic stuff; I'm talking strawberries, pineapples, clementines, grapes, just regular food that for anybody going through this of course they're not typically sitting down eating chocolate cookies and ice cream. There's a whole process of building up what they're willing to consume in that, so even access to food.

4.3.3.1.2. *Adolescent eating disorder service.*

When looking at the care provided by the adolescent eating disorder service there was only one barrier mentioned, with all the other comments being facilitators. It was mentioned that one health care provider did not take part in the team meetings, leading to a divide in delivering a unified approach to care.

Beyond this, participants mentioned that there was great follow up with the team, and that care was “very good” and a “glowingly positive experience.” One youth participant, *Amir* (youth) scored the service as “10/10” and said it was a “wonderful thing.” There was mentioned that there was a good rotation of doctors, the medical appointments were not rushed, and it appeared like the providers “really seemed to care.” The dietician was very helpful and experienced, and the social workers were helpful as well. The psychologist was the biggest part of recovery for one youth participant as his care with the psychologist was continuous and he could always access and communicate with his psychologist. Also, the team held meetings to discuss progress and determine a unified approach to care, which *Hilda* (parent) mentioned was an important part of this “incredible” multidisciplinary team. In addition to access to the adolescent eating disorder services, there was mention of increased access to other medical services through this setting as well such as dermatology. In summary, the quality of care from the adolescent eating disorder service overall is reflected in the following excerpt, “Overall, all I

can say is that our experience with the care and with the access to care was really quite excellent.”

4.3.3.1.3. *Outpatient program.*

When exploring service and care provided through the outpatient program there was a mix of barriers and facilitators mentioned. Regarding barriers, from some youth participants there was mention of unprofessional, and damaging experiences with providers at the program. For example, one youth participant said the service providers at the program made her/him feel ashamed and “horrible” about her/himself. There was also mention that some of the staff needed to choose their words more carefully as they can be triggering for some of the clients. For example, some participants also mentioned that the outpatient program could be a negative environment for refeeding, as the meal supports spurred competitiveness instead of support. One of the participants mentioned:

I found that in meal supports I would push myself to be the last one finished, and I would want to be the one who was having the biggest break down at the end of the meal. We would all compete and we would try, and you could see each other sitting around this table just comparing ourselves to each other. The illness just grew and grew and grew and I developed habits and eating disorder rules that I didn’t have before I went, like they taught me how to be a better anorexic there [at the outpatient program], basically.

Regarding the facilitators, several participants had good things to say about the program; it was “very beneficial”, “phenomenal”, and “everything about it [the outpatient program] was really helpful (Yvonne).” For some participants the program was the biggest step in resolving their eating disorders. This stemmed from the consistency of the program, the meal supports offered, and the psychological services provided. There were several discussions surrounding

how beneficial the psychologist at the program was, and that there were no limits to what she would do to help the participants. Although some participants are graduated from the outpatient program, they still can see the psychologist there, and as one participant put it “I still see [the program] psychologist because she’s the best one I had ever been too.” Aside from the psychologist, participants who graduated from the outpatient program articulated that they still have access to the centre if they need more support. It was articulated that the outpatient centre was a comfortable and safe environment, and that it was “kind of like home.” A youth participant said, “I still to this day love seeing them when I go in. And they hug me and it’s just a really personal bond that you get with these people.”

4.3.3.1.4. Internal medicine ward and emergency department.

Many of the participants who were admitted to hospital had to stay in the internal medicine ward until their vitals were stabilized, with other participants spending the majority of their hospital time in the internal medicine unit. The participants’ perceived quality of care received in these units varied, with some experiences being positive, and others being negative.

Several of the participants said that the service providers in this setting were not knowledgeable in eating disorder care, and lacked “caring” and “compassion” in their treatment. Insensitive commentary was common in this setting, such as “Another fucking eating disorder patient, I don’t understand why these people just can’t eat.” This along with other signs made these participants feel like they were wasting the staff’s time. Some participants also felt like the staff were looking down on them with pity, and spoke to them like they were children, which they did not appreciate. When there was dissonance with the provider many of the youth participants would refuse to talk to them, which had a negative effect on the relationship. Another barrier found in both rural and urban internal medicine wards was the lack of an eating

disorder protocol to observe individual's behaviour and eating. This was a barrier to care as an eating disorder protocol was seen as necessary for these youth to recover. Several participants had to request that their child be put on this protocol. Additionally, one participant had to fight to have her daughter return to the pediatric unit from the internal medicine unit for meal supports and other activities, mentioning:

It's a shame that people have to fight so much for these things. We could, and we would, and we did, but a lot of people wouldn't. I mean a lot of people would sit back and say 'Oh my gosh I can't meet with the head of this and this.' [They] wouldn't even think to do it, and again I think, but we had to fight to do that so again, how many people are out there not getting this care, or not getting consistent care because they're not fighting for it. And it's a shame to think you have to fight for those types of services.

One youth participant also mentioned that the staff left the food out sometimes, which would go bad, and at times staff would eat food off of the plate before serving it. Along with this lack of eating disorder protocol was the lack of "appropriate" food, which was mentioned by multiple participants. This forced parents to bring food into their child.

Participants had mentioned some positive experiences with care in this unit as well. Some of the service providers were very good, and often went out of their way to communicate, and care for the participants. One nursing student who was on rotation in this unit was "awesome", and had impeccable bedside manners. Also, the dieticians were found to be helpful, but often times were busy and unavailable.

Along with these experiences in the internal medicine ward, another participant had a "horrible, frustrating, and stressful" time in the emergency department. She felt there was a lack of communication between the health care providers. At times, it seemed that the various health

care providers were not letting her in on their reasoning as to why they did not want to admit her child. This participant felt strung along, and notes if there had been more open communication with her it would not of been as bad, stating “I guess I felt that I was being manipulated a little bit, or jerked around.”

4.3.3.1.5. *Family physician.*

After the participants had accessed more specialized eating disorder care, the family physician was really not connected to the rest of most of these journeys. There were varying experiences to care with family physicians, with some participants saying their physician was “exceptional” and “extremely supportive”, while others claimed their family physician did not take their concerns seriously and were a major barrier to care. Some of the participants stated that their family physician was not knowledgeable about eating disorder care, and they never really provided any instruction or guidance regarding what participants should do. With this being said, in some of these cases the physician did find out who was better suited to care for their patient, and made the appropriate connections, as supported by one participant “He [the family physician] knew what to do, he didn't seem like he knew a lot about the condition itself, but he knew who to contact and where to go.”

4.3.3.1.6. *Private psychologist.*

A handful of participants believed that their child’s private psychologist was “really helpful.” With this being said, there were many more participants who experienced a low quality of care with their private psychologist, who made the participants feel uncomfortable and shameful at times. The majority of these participants said their psychologist had little to no experience in treating individuals with eating disorders. Take for example one dyad that mentioned they had a “quite a disruptive” experience with the psychologist, who the participant

said “[was] more harmful than helpful at the time.” Overall, the quality of care provided by these psychologists was poor according to the participants.

4.3.3.1.7. The eating disorder advocacy organization.

The eating disorder advocacy organization provided care and support to families, along with education and resources. The participants mainly spoke about experiences they had with the organization staff, the emotion focused family therapy training, and the education and support group for parents. There were only facilitators mentioned and no barriers expressed in regards to quality of service with this organization. The services provided at this organization were “really invaluable”, and “very effective”, and to quote one participant, “oh my God I can’t even say enough about that, I can’t say enough about them.” Speaking of the staff, participants said they were “terrific” and went out of their way to personally connect with parents. The education and support groups proved to be “lifesaving sessions” and really helpful for parents. Parent stated that the group facilitators were excellent, and offered a sympathetic ear while the education provided was really good, and beneficial for all parents in the room. They also felt there were great resources and reading materials provided. For one participant, having access to the various guest speakers and health care providers was very important to gaining good information regarding specific issues. The quality of these sessions and the guest speakers were really good as well, and the facilitated discussion amongst parents was a substantial help. The level of service provided from the association was quoted to be very high, and incredibly helpful for parents.

4.3.4. Facilitators to Improved Health.

Aside from the items mentioned in the other sections of this interpretation, there were several additional elements that facilitated participants’ health improvement. Some of these items

can be classified under the topic of access, and some under care. This section provides an indication of common themes that arose from the major facilitators and recommendations, as there were several minor facilitators that may have been mentioned by a single participant.

4.3.4.1. *Activities and therapies.*

The participants mentioned a variety of different therapies and activities that helped them. Some of these activities provided them with an outlet for their emotions, while others provided tools to be better educated about their illness. The main activities that were mentioned by multiple participants were art therapy, writing, the use of music, and a variety of other sessions.

4.3.4.1.1. *Art therapy.*

When talking about art therapy, the participants did not necessarily find the therapy aspect beneficial, but enjoyed the process of making art. Art therapy in the hospital provided a place for participants to take their mind off of treatment, and also allowed participants to express their creativity. As one youth participant noted, “art therapy was really great and I loved it. I went on after that too, after I got out of the hospital, and I kept going with that cause it was really helpful, really great.”

4.3.4.1.2. *Writing.*

In exploring the benefits of writing as an outlet, *Amir* (youth) referenced the use of writing exercises presented in the book *Life Without Ed* (Schaefer & Rutledge, 2003). Another youth participant said he found it easier to get his words, and emotions out through writing, “with me since I don’t really talk to people much, an outlet like writing is really great because you can otherwise, the thoughts would just be way too much, and that’s not good.” One parent also mentioned their child felt “empowered” from sharing their eating disorder story through writing to various organizations, both health related and non-health related.

4.3.4.1.3. *Music.*

Music was a subject mentioned by a few participants as being helpful. One parent participant said, “she’s certainly done the music therapy and found that beneficial”, while another parent participant mentioned that music was a non-physical activity so there was no anxiety for her daughter regarding over-exercising. Another parent also summarized how music was helpful for his child:

The other thing that I always say saved our son was music. Now he didn't get any formal music therapy through this program but he's a musical person who writes and sings and plays his instruments and was in a band in high school. And being part of a musical community was incredibly empowering for him as well. It supported him in an emotional way that he wasn't finding elsewhere, and he was able to pour a lot of the anxiety and depression and everything into the song writing and come out the other side feeling really good. So if there were to be an augmented dimension I would recommend music highly as a way for kids to express themselves.

4.3.4.1.4. *Other activities.*

A few participants mentioned that group therapy sessions were helpful as well. These took place at the adolescent eating disorder service and through the outpatient program. One parent mentioned that her son seemed to be a natural counsellor, and ended up helping others in the group, which was also “good for his morale.” There were a variety of group sessions that participants highlighted as useful. When looking back, one youth participant says, “I didn’t think it was going to be helpful, but it was really helpful to hear everyone else’s story, and have people talk and actually relate to them instead of feeling isolated when talking to everyone else.” A few

of these helpful sessions mentioned throughout the interviews were: Acceptance and Commitment Therapy, Stepping Stones, Body-esteem, Emotions, Fit for Life, and Yoga.

4.3.4.2. Education/support sessions and emotion focused family therapy.

Nine of the eleven participants mentioned services provided through the eating disorder advocacy organization in their interviews. These services included education, resources, and other various supports. The main discussions encircled both the education and support group for parents, and the emotion focused family therapy workshops. There were several stories explaining how beneficial these services were for parents. The parents thought it was really beneficial to talk to other parents and to discuss practical advice such as what worked and what did not work for their child. Also a few participants remarked feeling somewhat better about their own situation when hearing stories from other families. One parent said that between the services offered through the advocacy group they had “total support”, and “felt really empowered” when they came out of those meetings. Also, the educational program had different guests every week, speaking on a variety of topics, which the participants felt “helped a lot.” These meetings helped parents gain a better understanding of eating disorders, and how to manage their child’s issues, while maintaining their own mental health.

There were also several participants who availed of the emotion focused family therapy sessions from the organization. *Veronica* (parent) said that she found this type of training “extremely beneficial”, and wondered why this training had not been offered to her at the very start of her journey. She said the training really taught parents about “how to approach things, how to address things, [and] how to steer away from those comments”, and it helped participants move away from the feeling of “walking on eggshells” around their child. With another parent thinking the sessions were “awesome”, and that the role-playing and acting helped him

immensely with his son who had an eating disorder, but also helped him manage with his other children as well. This training provided extra tools for the participant to do an even better job as a parent, and he thought the whole experience was “positive, positive, positive.” It was quite clear when analyzing the interviews that the services provided through the advocacy organization were highly appreciated by participants. This organization provided parents with more education, tools, and resources, which empowered these parents to better help their children.

4.3.4.3. *School.*

The topic of school was discussed in all of the interviews. There were both barriers and facilitators brought forth by the various participants, in terms of accommodation and the school environment. However, the focus in this section is strictly on the facilitators. Some of the participants indicated that the response from their school helped to relieve some stress in accommodating for certain things, such as being able to complete school work at home, write exams alone, and easily leave the school for appointments. One parent also mentioned that the homeroom teacher at her child’s school volunteered to supervise her child at recess and lunch. This was extremely positive as she did not have to pick her child up to supervise every meal. For some participants the guidance counsellor offered support as well. Overall, for some of the participants the school was very accommodating, which helped to ease some of their stressors.

4.3.4.4. *Motivation to change.*

A point mentioned as a facilitator was the youths’ willingness to get better. It was noted that this willingness to get better really guided the recovery process. *Yvonne* (parent) mentioned how the outpatient program had been incredibly helpful, however “it was really only useful because he [participant’s son] wanted to resolve it.” This idea became even more evident as his journey continued, when he heard that the lack of an “exceptional willingness” to get better was

a major barrier to care for other individuals and families. In addition to *Yvonne* and *Laura's* (youth) story, a separate youth participant mentioned that the outpatient program would not accept him/her because "I wasn't willing to get better at that point." This willingness to get better appeared to be a screening criterion for entry into the outpatient program, to which some participants had alluded.

4.3.4.5. *Turning points.*

In two of the participant journeys, there were certain events, which have been suggested as being major turning points. These included one youth leaving the province for a period of time, and a separate participant and her family going on a vacation. The result from both of these events was a major turnaround in the youth's eating disorder journey, leading to less time accessing specialized services and greater health improvements. After these experiences, participants' mentioned that "it's almost like an eating disorder doesn't exist in our home (*Veronica*)", and that after this experience it "just felt like opening up of, oh my God, we're okay now, and that was a turning point. That was a huge turning point (*Phil*).". These two stories show the benefits of spending some time out of the province, and not sticking to the same patterns day in and day out. These experiences also give hope for individuals knowing that in some cases a clear turning point can be evident and there is a path to recovery.

4.3.4.6. *Parental advocacy.*

Through the majority of the participant interviews there had been episodes of parent advocacy: for their child to access care, or to access improved care. There were three common cases where parental advocacy was apparent: reaching out to discover what/how to access specialized eating disorder care; advocating for their child to be on an eating disorder protocol; and in providing meals for their child to eat while in hospital. There were also other forms of

parental advocacy voiced through these journeys such as to policymakers in the education and health sectors.

4.3.4.6.1. Attaining access to services.

After exhausting resources from her family physician and the advocacy organization, one parent participant could not locate a clinical psychologist for her child. This parent reached out to her friends and family to connect with anyone who could possibly help her. Fortunately, a friend of a friend was able to provide the participant with a necessary contact, eventually leading to an appropriate psychologist for her child. Similarly, another parent participant had concerns about his child's eating issues, but after multiple visits to their family physician his son still did not receive a referral to a specialized eating disorder service. This parent took it upon himself to connect with the advocacy organization, where he became more educated on the available options. This prompted the participant to bring an outpatient program referral form to his next family physician appointment, which led to his child receiving specialized care for his eating disorder.

4.3.4.6.2. Eating disorder protocol.

The next two participants had to request for their child to be put on an eating disorder protocol when they were in the internal medicine ward. One participant said their child was admitted to this unit on numerous occasions, and on many of those occasions there had to be a request from the parent for the eating disorder protocol to be implemented. In a separate story, one parent had to meet with heads of the various departments to ensure her child was put on an eating disorder protocol, along with being able to return to the psychiatry unit from the internal medicine ward for meal supports.

4.3.4.6.3. *Appropriate food.*

The lack of access to “adequate” and “appropriate” food spurred two separate participants to bring their own food for their child to eat at the hospital. One of these parent participants said there was a complete lack of fruit, and she had brought in 100 pounds of fresh fruit on each of her child’s two hospital admissions. A youth story echoed similarly, in that his parents brought in every meal for him to eat during his three-week hospitalization. This youth mentioned it was “difficult” for his parents to continue to go to the grocery store, and bring the meals to the hospital, thus the hospital was a barrier to his care in this regard.

4.3.4.6.4. *Educational and healthcare departments.*

Additional experiences of parental advocacy were apparent in the next three experiences. One parent advocated for changes in her child’s physical education curriculum through meeting with the school’s principal, and physical education teacher. The appropriate changes were made to ensure the content was mindful of body image and eating issue concerns, and she further offered the services of a health care worker to help educate the staff on these issues. Another parent participant mentioned that she, and her partner advocated to various government officials, regarding the need for more resources, in regards to human resources and also for adequate food in the hospitals. A separate parent participant also participated in an activity where they were able to share their experience with various health care authorities, government officials, and other individuals who are positioned in the provincial eating disorder community. These aforementioned experiences show that the parents involved with these interviews advocated for their child’s well being, and for the well being of other children in the hospital, and education settings.

4.3.4.7. *Ideal journey.*

Every participant was asked what an ideal journey would have looked like for his or her eating disorder treatment pathway. When these responses were synthesized, there was a general consensus on how this journey would occur among participants, with only slight deviations from one participant to the next. This journey is summarized in Figure 4.

Participants mentioned that the first contact should be to their family physician if they thought they might be having eating issues. The family physician would then be able to direct youth towards more specialized care without any delay or waiting period. This specialized care could include a psychologist (who was specialized in eating disorder care) or could be services from the outpatient program or the adolescent eating disorder service. This psychological service would ideally be publicly available, but if not, participants said they would utilize it privately. These services should be able to help the individual into a recovery stage, however if an individual was becoming sicker than they should be able to easily access services in the hospital setting. When the individual starts to improve they should be able to transition back into the outpatient program or the adolescent eating disorder service to receive psychological support. In recovery, the youth must also be able to continue to have access to these specialized services in order to mitigate the chance of going back into a relapse. The participants also stated that specific eating disorder educational resources should be available to the youth family, school, family physician and psychologist throughout this process. Additionally support should come from both the family and school throughout this process as well.

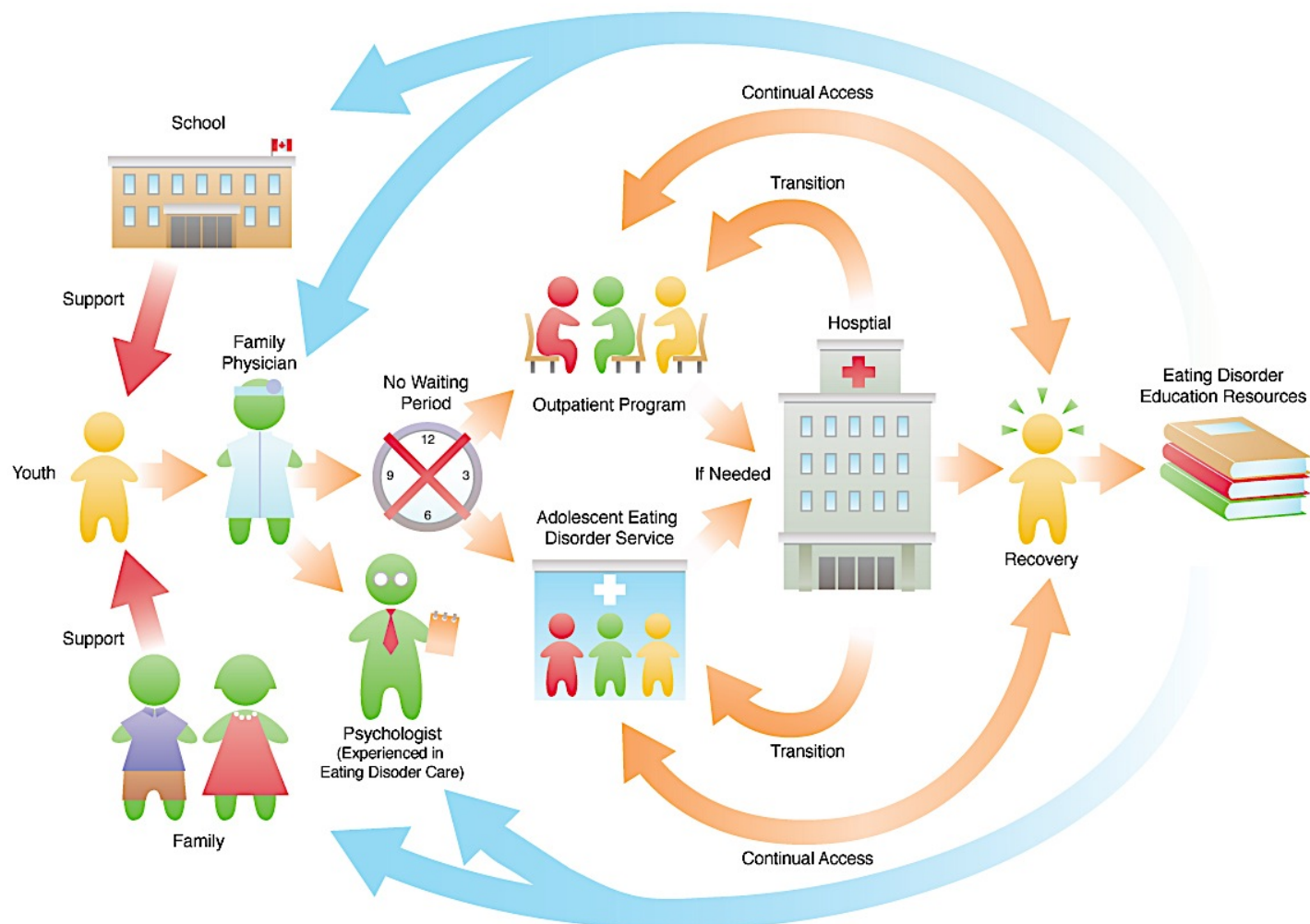


Figure 4. Composite Ideal Journey through Eating Disorder Services

Caption: The Figure illustrates the ideal journey to receiving care from the composite voice of all participants in the thesis project. The first step involves the youth accessing their family physician, who can direct them to a psychologist (experienced in eating disorder care), or can direct them (without having to wait) to the outpatient program or adolescent eating disorder service. From this stage the youth may be able to enter a recovery stage or may have to utilize inpatient services in the hospital. In the recovery period the youth must still have accessibility to specialized services in order to prevent relapse. Eating disorder education and support must be available to the youth, and their family; school; family physician; and their psychologist.

Additionally, the youth needs to be supported by their family and the school throughout this journey.

4.4. Multiple Voices.

A unique component in the current study is in the collection of the lived experiences from three different groups including youth, parents, and three dyads of both youth and parents. This additional level of interpretation shows some overlap and some differences in perspectives across these groupings. For instance, in comparing youth to parents, there were many congruencies in how a youth and parents articulated their story and journey. However, there were also details apparent in one journey that were absent in the other, and at times different factors were selected as main attributors to access and recovery. This concept is similar to those found in other qualitative mental health work that takes on multiple perspectives of parent and child. For instance, Kyriacou et al. (2009) found that parents and youth agreed on many items relating to emotional awareness and understanding such as the youth having oversensitivity to emotions, and difficulties forming relationships. These two groups differed in the parents remarking youth who had anorexia nervosa lacked in empathy while the youth cohort did not mention this theme at all in their discussion. This is interesting as in the current thesis there were certain events that parents included in their rendering of the journey that youth did not mention at all.

In this thesis, youth stood alone in speaking about specifics concerning care providers and their use of insensitive comments. For example, youth participants mentioned “Some nurses [in the hospital] would even talk about calories, and fat, and stuff that wasn’t very good in the situation”, and that “it didn’t seem like everybody was as educated on choosing your words wisely, cause you really have to be careful what you're saying to some of the girls cause they, they will look for anything, and then they will run with it and be afraid”, and also the following

being said in one of the health care settings “another fucking eating disorder patient, I don’t understand why these people just can’t eat.” This issue was brought forth by several youth, who alluded that care providers did not have the awareness or education about what should not be openly talked about for fear of triggering anxiety. Some parents also mentioned that they had learned what things to avoid speaking about through the parent support groups but they did not discuss a problem with health care providers making insensitive comments.

Parent participants tended to speak more about the issue of costs related to accessing services. In some of the youth conversations there was a light discussion around the topic “if I hadn’t gotten into [the outpatient centre], I wouldn’t have been able to continue with that psychologist, it was very expensive.” However, most of the parents spoke to the issue at length and as it was a point of focus in their interviews, such as how; “frustrating” and expensive the process of finding a psychologist was. This was echoed by several of the parent participants.

In examining the transcripts from the dyads, a unique set of divergences and observations were made. For instance, in one youth and parent story, the parent mentioned at length how beneficial their family vacation had been for their child’s recovery, in that this was a major turning point in their journey. However, the youth never mentioned this trip throughout their entire interview, and certainly did not highlight it as a turning point. It is interesting to observe that this turning point was discussed in such detail from the parent perspective, yet was non-existent in the youth’s rendering of her journey. Similarly, in another dyad, one parent spoke of how music was “really, really helpful” and how “music saved our [child].” However, the youth does not mention music at all throughout their interview. This is an area of divergence as well whereas the parent has viewed music as a pivotal part of the journey and the youth has not included music in his story. In a separate dyad, one parent discussed at length how

“phenomenal” her son’s motivation was for getting well. Even when speaking about how good certain services were, she noted “it was really only useful because he wanted to resolve it”, and she further went on to note that this willingness to get better was present throughout his entire journey right from the start, “He (the youth) really drove it, you know he was, he's the one who brought it to me, and then he took every step that was recommended to us.” The youth had mentioned the idea of his motivation to recover at one point in his story, but otherwise did not dwell on this point in the interview. This is unique in perhaps from an external and parental perspective the participant could really see how motivated her son was, and how he was a major facilitator to his own recovery. The youth certainly did not perceive his motivation to get better as a main facilitator in his recovery.

While there was some divergence, narratives did for the most part flow similarly from youth to parent in the dyad clusters. There was a discussion of early life, accessing a service or services, events throughout this service, discussion of school, and recommendations. When looking at the dyads, the early story was quite similar from both youth and parent. There were some small points of difference such as when a parent would fill in a bit more detail regarding a certain service provider. For the most part, the stories were all congruent in how the journey unfolded, such as with both participants in one dyad speaking of early isolation, and another dyad speaking about how the youth had spent their holidays, and their early eating disorder signs. Interestingly, in one dyad, both participants spoke in detail about the issue of the current obesity discourse, and it’s relation to the health education curriculum. They both also had extremely positive things to say about the adolescent eating disorder service. This idea of how care was perceived overall was congruent in and across dyads. Another dyad spoke about the benefit of the outpatient program, specifically targeting the work of the psychologist, “[the

psychologist was] the biggest step in resolving or getting her [his daughter] to the point that she's at now (parent)" and "she's [the psychologist] the best one I've been too (youth)." This example of congruency was observed again and again throughout the dyads. Even in some dyads, participants used the exact same phrasing, such as referring to the outpatient workers as "[the name of the outpatient program] zombies."

This multi-perspective interpretation brings a few thoughts to mind, ideas that are not rendered from looking at how youth or parents individually articulated their journey. For instance, the quality of the same care received is interpreted differently depending on perspective. Some participants from both youth and parent groups echoed similar thoughts towards care but the youth group appeared more emotionally connected to these opinions. In most parent cases, there were general sweeping comments made about care but the youth had more specific examples and more insight into the care process. As mentioned above, parents saw access to a psychologist as a major barrier because of the lack of availability and the cost. Some youth mentioned that the sessions were expensive but did not speak about this issue with the same vigor and detail as the parents. Both groups spoke about similar recommendations in increasing transition measures between services and education surrounding eating disorders for health care providers and the general public.

These considerations provoke more questions about why parents voiced elements of the journey with such detail and importance while youth did not address these elements at all. Is it perhaps that the youth believe these elements were not important for their story, or that they were not appropriate for the current study, or that the youth simply forgot this piece of their story. It is interesting that youth focused on the care or lack of care they were provided throughout these differing eating disorder services, where parents did not. Through reading the narrative

summaries, and the full narratives one can discern their own critical findings when exploring these multi-perspective stories of access and care, which will perhaps incite more questions than answers. This is a fascinating avenue for future research and/or in the follow-up interviews (as a part of the ACCESS-MH project) with the same participants over time. They could shed light on the similarities and differences in perspective that could be of use for targeting information, education and practice to each group.

4.5. Chapter Summary

The main thesis findings revolve around the discoveries from the narrative synthesis and thematic analysis. In creating these narratives, the voice of the participant was respected, and their story was not fractured. The narratives provided a context for the voiced barriers and facilitators to eating disorder services, with some participants articulating ideal journeys and others having journeys filled with struggle. Furthermore, some participants were in recovery, others were still managing their eating disorder, and others had lost all hope, such as one participant who said, “I don’t know what to do, I have no supports”. The thematic analysis highlighted the various barriers and facilitators to eating disorder service access and care. The major barriers were a lack of accessible psychological services (both private and public), the family physician, a lack of specific eating disorder education for health care providers, a lack of various resources such as capacity in the hospital, and a lack of public coverage of psychological services. The major facilitators mentioned were the support and resources provided through the local eating disorder advocacy organization specifically involving the emotion focused family therapy training and parent support group, the role of the family physician, the care provided by certain psychologists, the role of parental advocacy, and the treatment received from the adolescent eating disorder service and outpatient program. There was also an exploration of the

commonalities and differences found in the use of the studies multi-perspectives of youth and parent. It was unique that parents discussed certain events at length, yet youth did not discuss these events at all in their journeys. Also, it is apparent that youth showed much more emotion when exploring the role of the various service providers in their journeys when compared to the parent cohort. The similarities in both groups were in the chronology of utilizing services, and also in certain ideologies, such as how mental health education should be taught in schools.

There has now been a thorough explanation of these themes, in both the individual participant context and in looking across all of the participants. The next chapter is the Discussion and Recommendations, where there is an interpretation of these themes in comparison to the current literature and the complex cultural nesting theory.

Chapter 5: Discussion and Recommendations

This chapter includes an interpretation of the study findings in context with the literature, along with an exploration of the study recommendations, strengths and limitations, and a potential knowledge translation strategy. It positions my findings against those in the literature review to examine what is the same, what is different, and what this means to scholarship and practice in the field. I also return to the theoretical framework for interpretation and recommendations. Finally, I summarize the thesis implications and point to limitations and new directions in research and literature, followed by concluding remarks.

5.1. Interpretation

When examining the narrative and thematic analysis there are several items that are consistent with the literature and others that are novel. The emphasis in this section of the discussion is exploring the findings in relation to the main research question: *What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?* Some of these barriers and facilitators, such as family physicians, and the outpatient program acted in paradox similar to those paradoxical themes found in the literature (Boydell et al 2006; Tilleczek & Lezeu, 2014; Tilleczek et al., 2014).

In addition to this main research question, the findings are discussed in relation to the guiding questions: *What health services are these patient populations currently accessing? What services are they accessing through other agencies (e.g., education, social work, private sector providers)? What services are effective/ineffective and why?*

Previous literature contains one report that is particularly appropriate for comparison to the current study as it was positioned in the eating disorder field in an Atlantic Canadian province (Heath et al., 2006). The Report was sponsored by the Eating Disorders Working Group as a part

of a study named *Development of an Intensive Outpatient Treatment Program for Eating Disorders: a Cost-Benefit Analysis*. As a reminder, there were 12 patient participants in this report in addition to several health care providers. There are points of convergence and divergence between this report and this current thesis. When looking at the specific health care providers accessed, there was a prominence in usage of psychological services, and support in a group setting. However, art therapy was only utilized by a single participant in the report, but was used often by participants in the present study. This relatively lower use of art therapy, and no mention of music or writing as a therapy, was surprising because several participants in the current study mentioned these activities to be useful. Although psychiatric support was not mentioned as often in the current study, there was mention of services offered through the adolescent eating disorder services, which includes psychiatric and pharmacotherapy. Several participants in the report had accessed services provided through an out of province residential treatment Centre, where only one participant in the current study accessed services offered through an out of province residential treatment Centre. Perhaps this current low use of an out of province residential treatment Centre is because participants are now able to access specialized eating disorder support through the in province outpatient program, which was not available at the time of the report. This may also be due to the specific participants we heard from, and may illicit a different understanding if we were to repeat the study. Similar to the current study were the issues associated to missing school due to inpatient treatment. Additionally, participants also mentioned loss of friendships, and heightened levels of stress due to their disorder in the thesis; a common finding in the report as well.

Participants in the current study, especially those who accessed the internal medicine ward, articulated that service providers lacked eating disorder education, a finding also stated in the

report (Heath et al., 2006) and elsewhere in the literature (Tierney, 2008). In the report, the literature (Tierney, 2008), and the current study, health care providers were said to have made insensitive comments that were triggering for participants. Also, individuals in the report and other literature (Offord et al., 2006) felt that hospitalization was fine for physical needs but never investigated the underlying issues for their eating disorder, a point supported in other research as well. Whereas participants in the current study said that the outpatient program was important for examining mental factors related to their eating disorder, and in helping them come to a complete recovery, not just a physical recovery from their eating disorder. In the report (Heath et al., 2006), participants said that they had to wait six months for appointments, and there were no real supports in place. There were more supports in place according to participant experiences voiced in the current thesis as the outpatient program was suggested to be an appropriate treatment environment, and was developed in order to support only individuals who had eating disorders. This being said, there was still mention of a lack of resources from the system level in the current thesis, as also mentioned by both Heath et al. (2006) and Boydell et al. (2006). From some participants in the current study there were similar issues to the report in: the lack of availability of pediatric psychiatry beds, and a lack of resources such as adequately trained staff.

An issue that differed in both report and thesis was the need for a day program; as there is currently an outpatient program available for participants, which was not available at the time of the report. Also different in the current study is the issue of lack of coordination, as participants reported that care was coordinated for them at the adolescent eating disorder service, or the outpatient program. Additionally, there have been advances at present time when looking at the continuum of care, such as dedicated eating disorder beds at the pediatric psychiatry unit for an in-patient option, adolescent eating disorder service providers managing outpatient treatment,

and there is now an eating disorder outpatient centre that offers a day treatment program. This array of services was not completely continuous for all participants interviewed in the current study, but it is undoubtedly an improvement from the fragmented, general services available at the time of the Report (Heath et al., 2006). In the report, the participants thought an ideal system would include an intensive outpatient program with a multidisciplinary staff that was fully trained to treat both youth and adults who had eating disorders. This would be followed with a less intense program for individuals who were further down the road to recovery, which could then be followed up by a drop-in service should individuals need to access immediate support. At the present time, the outpatient program provides day treatment options with a full, dedicated staff. In the current study, there was discussion of transition programs from the hospital to the outpatient program, which could be an intensive program, and then from the outpatient program back into regular living, which could be facilitated by a drop-in service. These recommendations hold value for future policy, and have been included as recommendations in the current study.

There has been work carried out by the EDICCB team, which includes the Community Capacity Building Toolkit for Eating Disorders, which has built upon the report recommendations for more family physician education, and community capacity building. This community capacity building is still necessary according to the findings in the current study, and has been brought forth and addressed at the Provincial Government Eating Disorder Roundtable. When comparing the findings in the report to the current study findings, there are many points of similarity and difference. This exercise of comparison provides some optimism when looking at the changes that have occurred in regards to provincial eating disorder care through the past decade. Looking into the future, perhaps areas of concern in both the report and thesis can be targeted more effectively.

5.1.1. Facilitators And Barriers.

Both youth and parents have expressed several, multileveled facilitators and barriers to care. Some of these trends can be clearly identified as either a facilitator or a barrier, while others cannot be clearly identified as they are context dependent, and vary across participants. For example, some participants found their family physicians to be a facilitator to accessing specialized care, while others found that family physician to be a major barrier to care. Although there are appropriate specialized services available, many barriers still exist in accessing care within these programs.

There were three main categories found: Initially Accessing Care, Factors Affecting Care, and Facilitators to Improved Health. The sub-themes were appropriately positioned under each of these categories. Below is a more in-depth exploration of some of the major themes in comparison to the literature. Generally speaking, most of the voiced barriers and facilitators had previously been reported in the mental health literature. However, there were themes such as parental advocacy that were voiced extensively in the thesis and less so in the literature. And, there were experiences reported in the literature such as positive past experiences that were all but absent in the current study.

5.1.1.1. *Primary health care providers.*

Each participant in the current study had accessed his or her family physician at the start of his or her journey. These providers were an essential part of guiding their patients to appropriate care, and giving them the highest chance for recovery. One of the priorities recognized from the MHCC (2012) is to expand the role of primary health care in meeting mental health needs. For some participants their family physician knew the appropriate specialist to contact, and where to send the participant for care next, which was a big help. However, other family physicians did

not act, or delayed this referral process, which proved to be a barrier for the participant. This barrier was also observed in the literature where family physicians did not take the individual's concerns seriously, or they acted as a barrier to that individual receiving care (Evans et al., 2011; Heath et al., 2006; Tierney, 2008). Some of the participants mentioned that it seemed like their family physician was not knowledgeable about eating disorders at all. While others alluded to being their family physicians first eating disorder case, and they have since been able to provide better care for other patients who came in with similar issues. Education surrounding mental health care should be of utmost importance for primary care providers, who can provide effective early intervention, and direct patients to more specialized providers (MHCC, 2012).

The findings in this study concur with the literature in supporting the notion for more training for primary care providers (Heath et al., 2006; Linville, Brown, & O'Neil, 2012; Tierney, 2008) an idea that has also been recognized previously by the EDICCB team. This group offered education and support to help facilitate primary care providers to collaborate, and to provide effective care (EDICCB, 2012). This community capacity building program is appropriate for discussion in context of the current study findings because it addressed the need for family physicians to be better-educated surrounding eating disorder care, which is also brought up in the literature (Heath et al., 2013; Tierney, 2008). This program has reached out to rural and urban areas in one Atlantic Canadian province through workshops and conferences.

From the Provincial Government Eating Disorder Roundtable, there is support for the Community Capacity Building Toolkit for Eating Disorders (2014), which was developed for use at an eating disorder workshop. The feasibility of this eating disorder workshop showed positive results and can be further explored through Heath et al. (2013). It has been determined that actionable steps towards dissemination of the "Toolkit" to various primary health care

professionals is of high importance for prevention and early intervention in the province. A ‘how to’ action plan has been developed in order to update the material, and to increase uptake of the toolkit through various consultations with this interprofessional team, adolescent eating disorder services, the outpatient program, and the eating disorder advocacy organization. This toolkit is very comprehensive, and includes all the necessary tools for family physicians. As established through the eating disorder workshop (Heath et al., 2013) there would be a much higher level of eating disorder education and awareness in the province if this program could continue to reach primary care professionals, perhaps through an online source. This initiative may lead to a decrease in barriers, and an increase in facilitators provided through family physicians.

5.1.1.2. *Psychologists.*

The psychologist is a vital part of the multidisciplinary team. The care they provide for individuals involves a developed treatment plan, exploring the psychological issues underlying the eating disorder, and providing therapy to focus on improving patients' personal relationships (APA, 2011). Their support is critical for both patients and families, and cannot be overstated from the perspective of the participants in the current study. Psychological services were spoken about at length in most of the interviews, where only a few participants were able to easily access a clinical psychologist that had experience in treating youth eating disorders.

There were three main barriers identified in regards to psychological counselling: being able to access a clinical psychologist; the clinical psychologist having experience in eating disorder care; and the cost of accessing a private clinical psychologist. The literature does not report an extensive discussion of lack of clinical psychological services but there is reference to lack of human resources, which included service providers (Boydell et al., 2006; Heath et al., 2006). This barrier is unique because there was discussion from the majority of the participants

on issues stemming from psychological services, however there was not such an emphasis in the literature, which could possibly be due to the samples in the literature being different than in this thesis. This barrier related to psychological services is further supported in the context of Atlantic Canada as one provincial psychology association mentioned that there is currently only “one psychologist for every 2,000 people in the province” (CBC News, 2014, p. 1). The barrier to accessing a qualified clinical psychologist is partly due to the low number of practicing psychologists and the fact that psychologists that are practicing in the province are already at capacity with lengthy waiting periods. One public news story (CBC News, 2014) reported a case in which an individual who had anorexia nervosa was turned away from care, the then president of the psychology association mentioned that “the individual in question was unable to receive the psychological and medical care she urgently needed to treat her eating disorder” and the “incident is evidence of the challenge [the people of the Atlantic Canadian province] face in accessing psychological care.” (p. 1).

Some parents wanted to access these psychological services so both they and their child could start an intervention as soon as possible and to be better informed. This occurred for many participants during a waiting period to access publicly covered psychological services through the outpatient program or the adolescent eating disorder service. For some participants, there was no psychologist working as part of the adolescent eating disorder service, which forced them to go outside of the public system for psychological counselling. From the current study, this topic requires further exploration and discussion at the health administration, and provincial government level. Over the past year of discussions, the Provincial Government Eating Disorder Roundtable has recognized this issue, and has created an “Action Plan” for eating disorder services. The most recently updated “Action Plan” obtained from this Provincial Government

Eating Disorder Roundtable is from October 2014. This document addressed several of the concerns and barriers raised by the participants in the study findings. In the section allotted for Treatment there were three “Actions” that are relevant to the barrier of psychological services, these were: fill vacancies for critical functions as soon as possible with short-term measures; explore the possibility of expanding the Telehealth program to offer specialized eating disorder services for those individuals outside of urban centres; and to investigate options to address shortages, particularly for psychologists.

In exploring the first action regarding vacancies, a psychologist has been hired for the adolescent eating disorder service, and a psychologist has returned from maternity leave at the outpatient program. This document shows that the current public health program vacancies have been filled, which is a positive sign. However one participant mentioned that the need for multiple psychologists in these programs was apparent. In the action plan, there was also mention from the government that they are looking to increase recruitment and retention of psychologists through bursaries and signing bonuses. There have been some other strides made through the action plan in looking to increase capacity for psychologists to deliver care in the province. According to the action plan, one regional health authority is looking to set up their eating disorder outpatient centre with the necessary equipment to allow for telemental health support, and more specifically eating disorder services for individuals who are looking to access support in rural areas. Some of the literature that supports the need for more rural services includes works by McCormack et al. (2013) and Alman et al. (2014).

The second measure was in investigating options to address the gaps in psychological services. The latest update described this process as “ongoing” between regional health human resources, and the Professional Practice Coordinator for Psychology, and the Department of

Health and Community Services. There is room for some optimism knowing that there is already movement at the provincial government level on some of these issues recognized in the current study.

These action points from the roundtable identify the lack of availability of psychological services, but they do not address the barriers that come with having to pay for psychological services offered outside of the public system, which is necessary in many cases. In the current study, unless participants utilized psychological services through the hospital, the outpatient program or the adolescent eating disorder service, then they were not covered through public health insurance. These psychological sessions may be necessary for youth and their families, however they may not be accessible for example because the participant was not accepted to the program, or was in a waiting period. For some families, if they cannot receive these services through public health insurance, then they will not be able to cover the cost of these sessions out-of-pocket. In the present study, many of the participants used their own private health insurance to cover the cost of the first few sessions. However, in these cases the families usually used up their yearly coverage in the first four or five sessions. After they had used all of their insurance for these psychological sessions, they had to pay for the sessions out-of-pocket, and in some cases ended up costing the families a few or even several thousand dollars. This is a major barrier to care, and as one parent participant mentioned, “It’s [psychological service] basic health care”, which should be publicly covered. In examining the literature there was mention of lack of health coverage for services, and financial considerations associated with accessing certain providers, but this was not specifically directed to psychological services, and also these studies were positioned outside of Canada where public health insurance is quite different (Cachelin & Striegel-Moore, 2006; Evans et al., 2011; Sarvet, 2009).

In listening to these interviews, it was quite clear how difficult it was to access psychological services, especially outside of the publicly covered system. It was also noted how helpful these services were once they were accessed, and that an appropriately trained psychologist could be the difference in a child getting to, and staying in recovery. It would be an important facilitator to care if there was total or partial coverage for private psychological services from the public health insurance. It is interesting that this information was not widely cited in the literature reviewed, perhaps suggesting that this issue being quite prominent in this Atlantic Canadian province when compared to other areas.

5.1.1.3. *Waiting times.*

Due to the lack of a national registry for eating disorders in Canada, there is no true indication of the average wait times for treatment (Government of Canada, 2014). Although there has been no nationally defined average waiting period for accessing eating disorder treatment, there have been some waiting periods articulated in the literature, media, and from a national advocacy group. Waiting time was also a barrier expressed in the literature, with a variation in the amount of time an individual had to wait, with some waiting two months and others having to wait up to two years to access specialized service (Boydell et al., 2006; Heath et al., 2006; Leavey et al., 2011). According to a news source, “At the country’s largest in-patient program at Toronto General Hospital, the wait [time] is three to four months long for a woman five feet five inches tall and weighing only 60 pounds” (Kapelos, 2014, p. 1). In Manitoba, politicians have mentioned that wait times for treatment range between six and 18 months and they have said, “patients seeking treatment for eating disorders from a provincially run program are facing ‘unacceptable’ wait times” (Kusch, 2013, p. 1). According to the Canadian not-for-profit advocacy group, The National Initiative for Eating Disorders (NIED), regardless of

severity, there is an average four to six month waiting period for a hospital bed or for eating disorder treatment in Canada (NIED, 2015). The Report on Eating Disorders from The Standing Committee on the Status of Women in the House of Commons (Government of Canada, 2014) has recognized that the waiting period across Canada is too long, and that “tracking” patients at the federal level would improve the knowledge on the realities of how eating disorder treatment occurs. These wait times were for accessing specialized eating disorder care, not acute care. To summarize, they ranged from three to four, four to six, and six to 18 months.

It was recognized that the amount of time an individual is waiting for CBT is inversely proportional to how long they will stay in therapy and their chances of a full recovery from an eating disorder (Carter et al., 2012). Carter (2012) proposed that when a patient first receives a referral, their motivation to seek and gain treatment is highest. The longer the wait to see a specialist or start a treatment pathway, the less motivation the individual will have. Through waiting an extensive period of time to receive treatment an individual will be less likely to follow through with treatment into a recovery stage (Carter et al., 2012). In agreement with that point, according to the Canadian Mental Health Association (2013), the sooner an individual receives treatment for an eating disorder the higher their chances are for recovery.

Knowing this information is helpful in validating the importance of waiting times as a barrier to care in the current study. The waiting period for initial access to adolescent eating disorder services was from two to six weeks, while the outpatient program ranged from three to eight weeks. These waiting periods are much less than the waiting periods reported in other areas of the country and could be specific to the experiences of the thesis sample. However these waiting periods were determined from the time that an initial referral was made from a primary health care provider. Depending on the timing of this initial referral, participants waited up to

several months more to receive treatment, and in one case the participant had to wait a full year. Waiting for treatment was extremely taxing for these families, as parents watched their child become even more ill and began feeling like there was nothing they could do to help. Perhaps if there was more eating disorder education and appropriately qualified family physicians and psychologists available, then early interventions could commence prior to accessing more specialized care. In this regard there would be more support for individuals and their families during the waiting period, which might alleviate some anxiety for them and move the young people towards better care earlier in their journeys.

5.1.1.4. Timing and location of programs.

Another barrier to access was in the timing and location of the adolescent eating disorder services and the outpatient program. The time it took to access care was articulated as a barrier in the literature; as this required parents to take time off work, which also had an effect on their finances (Evans et al., 2011). Parents and youth communicated that because these programs were run during regular work and school hours it created two main issues in that parents had to miss work to drive their child to appointments, and youth had to miss school to attend appointments. Depending on which stage a participant was in their recovery these appointments were frequent, possibly daily. It was mentioned that some youth participants had high levels of anxiety in missing so much school, a point also recognized and supported from the Kartini Clinic for Disordered Eating (2011). A suggestion is in perhaps offering some youth group sessions or appointments in the evening, instead of during school hours. This idea could be suggested for either the clinic or outpatient program, which may also be beneficial for parents who do not wish to take more time off work to bring their child to these programs. The parent educational and

support groups are offered in the nights, so perhaps a similar notion could be followed for some youth sessions.

Regarding geographical barriers, one participant had to relocate to be able access the outpatient program. While other participants had heard similar stories of difficulties in distance and time for patients in rural areas to access care. In rural areas where there are no specialized eating disorder services, location is a prominent barrier to access (Boydell et al., 2006; Evans et al., 2011). However, as discussed previously, the health authorities are looking to extend their Telemental Health Service to operate out of the outpatient Centre, which will hopefully help to increase access to those in a rural setting.

Recently the eating disorder advocacy organization has attained access to an apartment that they are providing for individuals who are relocating for eating disorder treatment (Organization Staff, personal communication, October 8th, 2014). This certainly helps to reduce the burden of finding and paying for a place to stay during treatment. In exploring the effect of geography and treatment, *Travel Distance and Attrition in Outpatient Eating Disorders Treatment* was useful (Swan-Kremeier, Mitchell, Twardowski, Lancaster, & Crosby, 2005). This study examined the impact of the distance participants had to travel in order to receive treatment with their rate of dropping out of the treatment program. The finding was that there was not a significant difference between distance travelled and attendance patterns or with completed treatment and incomplete treatment (Swan-Kremeier et al., 2005). This may be similar in the current thesis as only one person had to travel a far distance in order to receive care, and this person did not stop attending treatment due to distance.

5.1.1.5. *Eating disorder knowledge.*

There are several studies in which participants mentioned a barrier to their accessing a service due to lacking the knowledge of what services were available, or lacking general knowledge about mental health (Barker et al., 2005; Boydell et al., 2006; Cachelin & Striegel-Moore, 2006; Rickwood et al., 2005; 2007; Thomson et al., 2014). This finding was also apparent in this thesis in that several participants lacked knowledge about what services were available. Several participants also said their primary care provider was not aware of what services were available for patients who had eating disorders, a point not widely found in the literature reviewed. Parents and youth alike took part in activities to further their own knowledge surrounding care and treatment options through Internet searches, connecting with an advocacy group, or speaking to their social networks.

In certain scenarios youth participants used Internet searches to look up “pro-Ana” tips, or “how to be an anorexic” videos, in which case the Internet acted as an accessory to the further development of their eating disorder, which is consistent with the literature (Wilson, Peebles, Hardy, & Litt, 2006). However many also used the Internet to learn more about treatment options. Actions to further eating disorder knowledge through the use of the Internet have been observed in the literature as well (Thomson et al., 2014). These participants searched for answers to some questions that are similar to this study’s guiding questions, such as: what other health services are patients utilizing, are these through other agencies, and are these services effective? Through these searches participants found that the most common service utilized was from a clinical psychologist. Through reaching out to family, friends, work colleagues, advocacy groups, the Internet, and through their primary care providers some of the participants were able to locate, and access these psychological providers.

It was this acquisition of knowledge that acted as a facilitator for these participants to access psychological counselling. Reaching out to community, and advocating for more knowledge was an idea also observed in the literature (Boydell et al., 2006). We can see that acquiring knowledge from outside of the public health system may help individuals to locate services that are useful, and furthermore which are available.

Several participants also spoke about how they and/or their child had initially recognized that they were having eating issues, which led to a discussion surrounding their well-being, and then to an appointment with their family physician. Recognition of their eating disorder symptoms was an important facilitator to accessing care for the study participants. This finding is in line with a major recurring barrier to accessing care in the literature, which is a participant's lack in recognition of their eating disorder symptoms (Biddle et al., 2007; Cachelin & Striegel-Moore, 2006; Rickwood et al., 2007; Thomson et al., 2014).

5.1.1.6. *Patient-provider relationship.*

There are a variety of studies exploring the role of the patient-therapist, or patient-health care provider relationship as an indicating factor for eating disorder patient's dropping out of treatment (Evans et al., 2011; Heath et al., 2006; Helms, 2003; Lindsey & Kalafat, 1998; Tierney, 2008). One example of a barrier found in the literature was related to dissonance between patient and health care providers (Leavey et al., 2011). In opposition to this, a positive relationship between patient and provider proved to be a facilitator (Lindsey et al., 2006; Rickwood et al., 2005; Timlin-Scalera et al., 2003).

Several study participants spoke about the various relationships they had with providers in the hospitals, the adolescent eating disorder service, the outpatient program, the advocacy association, and with their family physician and private psychologist. There was a mix between

whether participants felt each of these relationships were good or bad, or if they had a positive or negative relationship with these health providers. The only provider that was consistently observed as a facilitator was the local advocacy organization. They were quoted as being an extremely “important piece of the puzzle” in guiding individuals to appropriate care and in providing education, a sympathetic ear, and resources to parents. For some of the youth participants, there seemed to be a very passionate distrust and/or anger towards certain providers, where this same emotional intensity was not apparent from the parental cohort. This was mentioned in the literature which suggest that patients felt a natural distrust of their health care provider (Boughtwood & Halse, 2010; Rickwood et al., 2007).

The dyads all seemed to be in agreement regarding relationships with providers. For example one psychologist was a main facilitator in one youth’s recovery, while another counsellor was perceived as not being adequately trained for treating the youth who had an eating disorder. In some situations, a youth participant said they felt frustrated with their provider at the time, but retrospectively felt the service was helpful. The importance of these relationships from the participant’s perspective cannot be exaggerated. In many of the journeys, the participants point toward a positive relationship as a main facilitator to recovery, where others indicated a negative relationship pushed the progression of their eating disorder. These findings are consistent with the literature, which suggest providers who acted empathetically, and took concerns seriously resulted in more positive patient experiences (Evans et al., 2011; Leavey et al., 2011; Lindsey et al., 2006; Rickwood et al., 2005; Timlin-Scalera et al., 2003).

5.1.1.6.1. Service provider characteristics.

Factors Affecting Care was mainly related to the characteristics and actions of service providers. The service provider’s characteristics and actions could act as either a facilitator or a

barrier to whether a participant had a positive or negative care experience. Many of these characteristics mentioned by participants were also voiced in the literature and included acting professionally (Evans et al., 2011), being empathetic (Colton & Pistrang, 2004; Evans et al., 2011; Tierney, 2008; Van Ommen et al., 2009), and providing guidance and various treatment options (Evans et al., 2011). Some barriers mentioned by participants, and also found in the literature, included a lack of trust in their provider (Rickwood et al., 2007), and a provider not taking their concerns seriously (Evans et al., 2011).

In the literature, there was a wide exploration of personal characteristics, such as providers' demeanor and the time they took to see the patient being some examples that acted as facilitators or as barriers (Helms, 2003; Lindsey & Kalafat, 1998). Participants also spoke of other facilitators that are related to this area and which have also been reported in the literature. They include having a provider who is experienced in eating disorder care, who operated out of an experienced multidisciplinary team (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen et al., 2009) and who delivered personalized care (Boydell et al., 2006).

5.1.1.7. *Stigma.*

When exploring barriers to help seeking and accessing mental health services in the literature, the most referenced issue was of stigma associated with mental health (Aisbett et al., 2007; Boyd et al., 2007; Boydell et al., 2006; Cachelin & Striegel-Moore, 2006; Evans et al., 2011; Francis et al., 2006). Both youth and parent participants also voiced stigma as a barrier to accessing services in this thesis. There was a desire to have mental health stigma be better addressed in the school setting, because this stigma at times made youth participants feel isolated, and not belonging to any group. This being said, stigma was not a major recurring barrier voiced by participants, with it only being mentioned in a few of the interviews.

5.1.1.8. *Motivation to change.*

The motivation to change or lack of motivation to change was apparent in several of the participant interviews. This motivation acted as both a barrier and facilitator to accessing services and to overall youth recovery. Motivation to change was an internal facilitating force for some youth. This being said, the lack of this drive acted as a barrier to program entry for one youth participant, and also hindered other participants from moving forward with their treatment. This idea is not novel, as it was echoed that the lack of a willingness or desire to get better was a barrier in patient experiences throughout the literature reviewed (Colton & Pistrang, 2004; Evans et al., 2011; Tierney, 2008).

5.1.1.9. *Strict program entry criteria.*

Throughout the literature, there were experiences where individuals pointed to strict program entry criteria as a barrier to their accessing care (Boydell et al., 2006; Evans et al., 2011). Three participants in the current study mentioned how strict program admission criteria acted as a barrier to access for them. An example of the criteria which denied participants entry included participants not being within a certain BMI range for admission, or that they lacked a willingness to get better.

5.1.1.10. *Advocacy.*

Advocacy was a topic brought up throughout the interview process, mainly referring to parental advocacy. This was a major facilitator to youth accessing and receiving appropriate care. Take for example instances where parents advocated for their child to attain a referral to specialized services, and times when parents advocated for their child to receive better care in the hospital setting. Parents were willing to fight for the services they believed would help their child, and in many cases they believed this advocating did make a difference. When reviewing

the literature, parental advocacy was rarely discussed, however it was mentioned as a facilitator in one study (Boydell et al., 2006).

A unique example of this advocacy was in parents bringing in food to their child in the hospital. There was mention that the hospitals did not provide adequate and appropriate food for the patients, which is something that was not mentioned in the literature. Perhaps this experience is unique to the local sample, however it is a point that warrants further exploration.

5.1.1.11. Past experience.

Throughout the literature participants have alluded to the influence of past experiences either negative or positive, acting as a barrier or facilitator to their accessing further mental health care. The positive experiences were seen as major facilitators in accessing care in the literature, however there was no real discussion of this facilitator in the current thesis (Lindsey et al., 2006; Rickwood et al., 2005; Timlin-Scalera et al., 2003). Conversely, negative past experiences were seen as a barrier to help seeking (Leavey et al., 2011), which was mentioned by a limited number of participants in the current study. Perhaps in the literature there were older participants who had utilized previous services for care, whereas the youth in the current study had more recently accessed services, leading to a limited past experience.

5.1.1.12. Peers.

There was mention in some of the journeys that peer support gained in the various care settings was helpful. One parent participant mentioned how helpful this peer support was in the hospital, while others mentioned this was important in the outpatient program. This idea of positive support from others in the care setting was also noted in the literature (Colton & Pistrang, 2004; Offord et al., 2006; Van Ommen et al., 2009). There was also mention of the opposite as well in these interviews, in that other patients helped create an environment of

distress and competition, and that these peers thus contributed to a negative patient experience, which is also commonly found in the literature (Boughtwood & Halse, 2010; Colton & Pistrang, 2004; Offord et al., 2006).

5.2. Recommendations

There have been several recommendations voiced from the participants in regards to how to improve care, and better reorganize the current system. Some of these recommendations are aimed at improving access and care, while others are speaking towards mental health education in schools, and so on. Similar to findings by Tilleczeck and Campbell (2014), the current study found evidence-based and programmatic gaps in the system. These recommendations focus on how access could be improved through identifying where increased program implementation, integration, and coordination can occur. Individual participant recommendations have been created, and were analyzed individually, and as a part of the overall participant voice. The recommendations in the tables below are positioned to either direct individuals as to what participants deemed as helpful, or as improvements suggested specifically to increase access, and care in eating disorder services. The bolded recommendations are the ones most highly recommended due to the frequency that participants mentioned, and based on the researcher's interpretation.

These recommendations are suited for a variety of readers looking to improve access such as individuals who have eating disorders, families, advocacy groups, health care professionals, policymakers, and government officials. In returning to the theoretical framework, the recommendations are organized in tables in accordance with Bronfenbrenner's (1979) and Tilleczeck's (2011; 2014) ecological and cultural nesting models for clarity.

Access to appropriate health services is extremely important for individuals who have eating disorders to *become* better. Through the current work and use of the complex cultural nesting theory, it is apparent that there are many factors and levels of factors that influence access to services. These have ranged from individual to service and school factors, to system policies, and ideological beliefs.

This theory helps clarify that access to eating disorder services are experienced *with, for,* and *by* youth and their families, and furthermore, how these barriers are experienced, such as family physicians not referring youth to specialists, lack of psychologists in the field, and lack of capacity in the hospital setting. This social analysis helps to make sense of these dynamic, complex stories, as they are located within the school, health service, community, and familial settings. It gives further insight into how access to, and care in treatment has helped some of these marginalized youth such as *Laura* and *Amir* make transitions into recovery (Cartmel, Biggart, Sweeting & West, 2003; Tilleczeck, 2014).

Access is multileveled and cannot be pinpointed to a single service provider or service, as barriers and facilitators to access exist at all levels of the ecological framework of development (Bronfenbrenner, 1979). In the present inquiry, the complex cultural nesting theory has helped to organize the multifaceted, intricate experiences youth have with Atlantic Canadian eating disorder services (see Figure 5.).

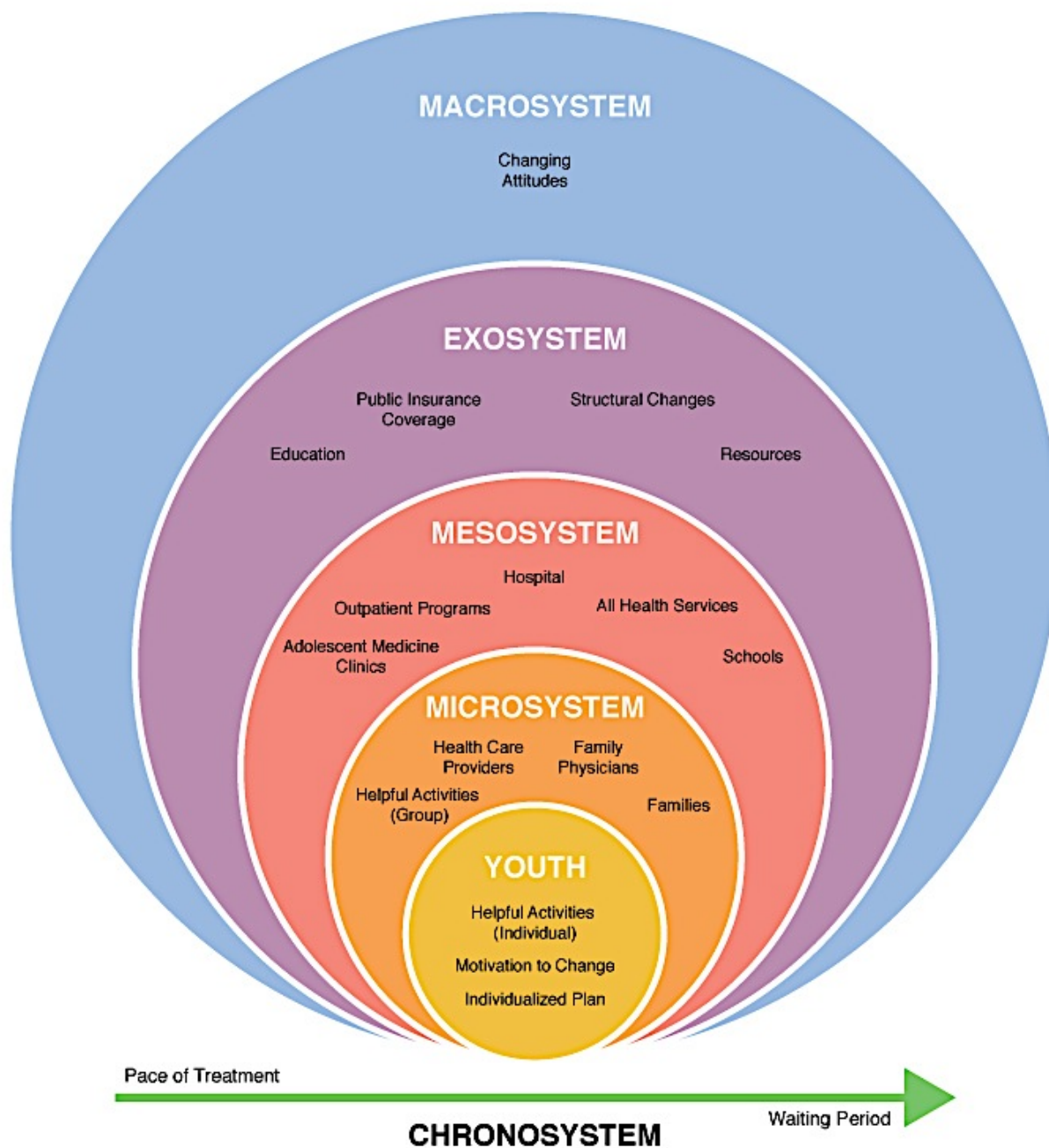


Figure 5. Recommendations From Participants: Complex Culture Nesting Model

Caption: The Figure shows how the participant recommendations are situated in context of the various ecological stages. The specific recommendations can be explored through the various corresponding tables.

Table 3. Recommendations for the Youth

Helpful activities (individual)	Motivation to change	Individualized plan
Sharing story publicly can be empowering	Drives recovery	Everyone needs a unique treatment plan to accommodate for his or her specific journey
Art, music, and writing as therapies	Self-awareness when struggling	

Table 4. Recommendations for the Microsystem

Helpful activities (group)	Health care providers	Family physicians	Families
Group therapy can be helpful if offered in right environment	Need to provide more compassionate and sympathetic care	Need more awareness of eating disorder services available	Need an integrated family approach to treatment- parents receive eating disorder education right away
Emotion focused family therapy was useful for parents	Need more education and awareness on insensitive comments	Need more education on eating disorder recognition	Need to take time to speak with child and listen to concerns
	Need to provide more specific practical advice and guidance to youth and family	Need more serious proactive discussion with teenagers about body image and eating status	Need to connect with eating disorder advocacy organization-to get resources, guidance, and support
		Need to refer patients that they even suspect have an eating disorder	Parents need to continue to advocate for better services and access for their child
			Families should provide opportunities for their child to regain autonomy- may result in turning points

Table 5. Recommendations for the Mesosystem

Adolescent eating disorder services	Outpatient programs	Hospitals	All health services	Schools
Multidisciplinary team is very helpful-increases quality of life with all service providers in same location	Difficult for youth and family to constantly access program during the day time hours-need to consider alternative program hours	Need better communication with family in emergency department	Need access to services in recovery stage	Need to be more accommodating-helping to supervise recess and lunch meals
Need at least one but ideally more psychologists as a member of this service	Recommended for youth, especially for the psychological support	Need to provide more specific practical advice and guidance to parents	Need more education and awareness on insensitive comments	Participants mentioned more empathy from the school in listening to their story and situation would help
Recommended for youth and parents	Three-week interview process is long-need to consider a way to streamline this process	Need an eating disorder protocol in all hospitals, and patient should be placed on this without parent having to advocate	Difficult for youth and family to constantly access programs during the day time hours- need to consider alternative program hours	It would be helpful if the school could be reorganized to help reduce social anxiety, and make the setting more familiar to youth
Difficult for youth and family to constantly access program during the day time hours- need to consider alternative program hours	Need more resources-increase capacity of program, and awareness	Need more eating disorder specific training, especially in internal medicine ward	Need a more multidisciplinary approach in all services, as this has been voiced as the best way to help individuals	Need more education on mental health led by professionals in the school for staff and students
		Need more appropriate food for eating disorder patients	Need more early intervention support from primary care providers	Need equal focus on mental and physical health in school

Adolescent eating disorder services (continued)	Outpatient programs (continued)	Hospitals (continued)	All health services (continued)	Schools (continued)
		Need improved organization amongst different health care providers in emergency room	Need to minimize transitions in care, and if not possible need to have transition protocol/programs in place to ease the transition	Need more support and guidance from guidance counsellors
		Need more capacity in psychiatry unit	Need to explore the feasibility of a more intensive day treatment and a drop-in service options	Need more guidance counsellors in the school
		Staff in psychiatry unit need to be more diligent in watching patient	Need more eating disorder specific training	
		Activities and therapies offered in psychiatry unit were seen as helpful		
		To not show discharge video to patients as it is seen as inappropriate in the Psychiatry unit		

Table 6. Recommendations for the Exosystem

Education	Public insurance coverage	Structural changes	Resources
Physical education needs to focus more on well being, staying healthy, and positive body image	Out of province residential coverage needs to be clearly written out and articulated for parents travelling with their child prior to accessing this support	Need more transition programs between services	Need more psychologists- publicly and privately
Schools- need more focus on mental health, provided through workshops by professionals	Coverage for out of province residential treatment should not be isolated to a single treatment centre- may not be the appropriate for everyone	School systems – need to stop isolating teenagers (junior high)	Need more psychologists who are trained in eating disorder care
School prevention programs should be mandated within the provincial curriculum	Need coverage for private psychological support- especially when access to an appropriate publicly funded psychologist is not possible	Program timing- feasibility of alternative hours for services	Need easier access/a lessened wait time to see a psychiatrist
Health care staff need more education on eating disorder care, and what topics to avoid openly discussing		Need to reduce waiting periods to the outpatient program and accessing the adolescent eating disorder service	Need more capacity in the outpatient program

Education (continued)	Public insurance coverage (continued)	Structural changes (continued)	Resources (continued)
Nursing, medicine, and social work programs- students should listen to youth eating disorder stories to provide the students with context for future care			Need more guidance counsellors in the school, and an increase in safe space for students to utilize
Psychologists need more specialized training for eating disorder care			Need more adequate, and appropriate food for refeeding of individuals in hospitals
Primary care providers need to learn more about eating disorders, and available services, perhaps a reinvigoration of the community capacity program			More awareness for current services to treat depression and anxiety- common in eating disorder patients
Needs to be more awareness and education in the general public around mental health and eating disorders- educational programs at the community level and more pamphlets in doctors and dentist offices			Need more capacity in the pediatric psychiatry unit, with more specific training/resources to treat eating disorders
More emphasis on the prevention side- create a culture of good mental health through awareness campaigns such as http://www.understandnow.ca/			Need to focus resources on education of staff and students towards mental health and eating disorders in school
Credible Internet sources need to be provided to families and youth			Explore offering eating disorder services in other parts of province- difficult for individuals in rural areas to access services
			Need to expand the use of technology to help individuals across the province access supports

Table 7. Recommendations for the Macrosystem and Chronosystem

Changing attitudes	Waiting period	Pace of treatment
Eating disorders can be sensationalized and romanticized in the media- need more education in the public to inform about the realities of eating disorders	Outpatient program- needs to look at possibility to streamline their interview process	Every journey is unique and requires special attention to best suit the individual
Stigma associated with having an eating disorder acted as a barrier to help seeking for some youth- need an increased awareness and education to target stigma; understand what eating disorders are and who they affect, and treatment options	If primary care providers even suspect an eating disorder- they should refer youth on to more specialized providers	Treatment goals must not be rushed- each person will have different triumphs and challenges, which will affect the speed of their recovery
Attitudes concerning obesity, body image, and “beauty” must also be addressed- youth felt that seeing their parent’s on a diet, or never complimenting themselves can be detrimental to how young people perceive themselves	More communication from emergency department workers may help in keeping families informed as to why they must keep returning for care, or have to wait several hours to be seen	Recovery must occur at a pace that the individual is comfortable with, and in a healthy manner
	While youth are waiting for their initial adolescent eating disorder service appointment perhaps family physicians can provide them with more resources and guidance so they can learn more about eating disorders, and reduce their anxiety in the waiting period	

5.3. Limitations And Strengths

Exploring the limitations and strengths of the current study can provide insight into future directions. Perhaps new directions can continue in this qualitative work by replicating this study in other areas of Atlantic Canada. This would provide more context to the triumphs and struggles experienced in these other provinces. Also, perhaps more perspectives could be captured such as: more male participants, adult service users, service providers, siblings, and educators to list a

few. Hopefully the current study can help to guide the process for other similar sub-studies positioned under the ACCESS-MH project. The interviews were with targeted samples that could provide rich information, and specific examples of experiences in the system. The present study did not look to collect prevalence and incidence data but was positioned to explore the personal stories from those who had first hand exposure to the specific health services in Atlantic Canada. Similar to all qualitative research is the intent to describe rather than predict. The results obtained are not to be generalized but could be in part transferable across Atlantic Canada.

5.3.1. Limitations.

In the current thesis, there are three limitations that are related to narrowing the scope of the study. First, when exploring eating disorders, only participants who had anorexia nervosa or bulimia nervosa were within the inclusion criteria. The reason for only choosing two eating disorders was due to limiting the scope of participants to focus the Master's project, and also anorexia nervosa and bulimia nervosa were the two eating disorders treated at the specialized services, such as the outpatient program. However, this decision regarding including only two eating disorders in this study limits a large portion of the eating disorder population who has been diagnosed with binge-eating disorder, avoidant/restrictive food intake disorder, or an other specified eating disorder.

There is a limitation in studying only services for youth, which has been defined as 15 to 24 years old (United Nations, 2014). Eating disorders are mainly found in adolescent and the young adult population (WHO, 2004), but there are still many individuals excluded from the study who are over this age range. Thus the area of adult care and treatment was not fully explored. These two limitations were taken into consideration at the design phase of the project,

but were not included due to resource restrictions, along with attempts to keep the study under a manageable scope for a master's thesis.

The last limitation related to the scope of the study is in recruiting those individuals who have not been able to initially access the healthcare system. Therefore, individuals may have an eating disorder but have not received a formal diagnosis yet. These individuals have an important story to share, however if they have not been/or are in the process of being diagnosed they will not fit the inclusion criteria as a participant.

These three limitations are important to note. They show that the current study is limited in the total scope of participant stories, and that the accounts collected only come from participants with two forms of an eating disorder in a population with a cut-off age of 24 years and younger, and from those individuals who have already accessed the system. These participants who are excluded from the study have valuable experiences and perspectives to explore and their narratives are not captured in this study. The question remains as to what their exclusion means to the findings as presented here and in the literature.

Also, it is important to note that some of the participants in the study experienced treatment a few years ago. This is essential to know because the health system is constantly evolving. These participants' experiences with service delivery and/or staffing may be different from the way patients currently experience care. There may be new staff involved and/or new policies implemented which would make for a different treatment experience and overall journey. Additionally, there are limitations in every sampling technique. In the present study purposive sampling was utilized in order to invite youth and parents who had rich experiences with eating disorder services and a willingness to share their stories with a researcher. However, the perspectives of certain individuals may not have been properly represented. For example,

individuals who had a poor experience with the system may not want to be a part of the study, and thus their experiences and frustrations cannot be properly documented. Also, our sample did not have a balance between male and female participants. Recruitment was achieved by asking participants to contact the research team and unfortunately this limited the distribution of male and female participants. However, the literature (WHO, 2004) states that eating disorders are more prevalent in the female population than the male population and this may explain why we received more women than men in our study.

A final limitation is related to my characteristics as a researcher in carrying out body-related research (Rice, 2009). Characteristics such as being a male, being a young adult, and having a slender build may have had an influence on participants. It is possible that participants provided certain responses to me as a researcher, which may not be otherwise have been rendered from a researcher who had different characteristics. Perhaps my position and standpoint may have led participants to feel increased trust with me as I am a young researcher or perhaps due to my slender build and being a male there may have been a form of competitiveness created amongst participants. These are purely speculations, but it is important to note that some of these ideas could have possibly influenced participants in this study, and thus acted as a limitation. This is a limitation that is present no matter who is conducting the research, but must be noted for the readers benefit.

5.3.2. Strengths.

The use of multiple perspectives is one strength of the current study allowing for a brief examination into the differences in how youth and parents perceived access and care. Also, through the use of dyads there was an opportunity to analyze some of the differences and commonalities from two perspectives on the one journey. Another strength of the current study is

that there is little literature exploring eating disorder access in the youth population. Through the literature review it is apparent that some work exploring barriers and facilitators in eating disorder treatment has occurred within the adult population, but little within the youth population, and less specifically looking at access in Atlantic Canada. This allows the current study to report contributable findings that are novel to the eating disorder and mental health community.

Another strength of the study is that it is located within a larger research project, ACCESS-MH (Tilleczek et al., 2014). This allowed for proper training in qualitative techniques, and opened up access to a wide number of resources that may not otherwise have been possible. Also, the protocol and other documents for the current study were derived from this larger project, which were created with a high level of rigor and from experts in qualitative techniques (Tilleczek & Bell, 2014).

Connecting to the eating disorder community was very beneficial for learning more about the current set up and also in being able to reach out to key stakeholders for recruitment of participants. The outpatient program and eating disorder advocacy organization were very open to communication to help inform the researchers, and allowed entry into their environment to provide insight into how their set up was structured. The research exchange group offered a plethora of insight into current research in this field in the province, and also into what appropriate literature already existed. The eating disorder advocacy organization was critical in reaching participants for recruitment, as the majority of participants had articulated they received information about the study from this organization.

Having a single researcher connecting with the eating disorder community, recruiting, collecting the information, analyzing, and writing up the findings increased consistency in the

study. Only having one individual carrying out the research made correspondence easier for the organizations and participants. Also, there is a heightened level of credibility in the voice of the primary researcher who has made clear that he has experienced eating disorder services from personal experience in Atlantic Canada. This experience also allowed participants to gain trust and feel more comfortable in the interview setting.

5.4. Knowledge Translation Strategy

Dissemination of the study will continue to occur on a variety of levels. A summary of the findings will be sent through electronic mail to the participants and if there is a more convenient distribution method suggested by a participant, this shall be followed. There will be attempts for peer-reviewed academic journal publications and presentations at academic conferences. As a part of the knowledge sharing mobilization strategy, the findings will be presented with Memorial University of Newfoundland, the research exchange group, and to the local advocacy organization. The study will be forwarded on to appropriate members at the Provincial Government Eating Disorder Roundtable, who have affiliations in the health, and education sectors. The findings of this thesis will be a part of the larger ACCESS-Mental Health project which itself has an assortment of dissemination strategies, including; providing information online (<http://access-mentalhealth.ca/>), through a short video format, and through various academic means. This CIHR-funded project has established connections with appropriate policy makers and government officials, which is important for distribution to decision makers.

Distribution of this thesis data has already occurred at the PriFor primary healthcare research forum held in St. John's, Newfoundland and Labrador in September 2014, at the 3 Minute Thesis Competition at Memorial University of Newfoundland in October 2014 and through a workshop at the 2015 Atlantic Summer Institute (ASI) Conference- *Investing in Child*

and Youth Mental Health – Mobilizing Atlantic Canadians for a Positive Future in Prince Edward Island. The findings from this thesis have also been accepted as a poster at the XXIst Annual Meeting of the Eating Disorders Research Society in September 2015 in Taormina, Sicily, Italy.

5.5. Concluding Remarks

There are many factors that influence access to eating disorder services for youth. Access to care was the main component of investigation in this thesis. However there was also exploration into what participants deemed good quality care. A clear picture of how this small group of youth and parents experienced care in Atlantic Canada was gained through this exploratory, narrative approach. Facilitators, barriers, and recommendations were discovered through these conversations, with main barriers being a lack of psychological services, guidance from family physicians, resources/capacity, public coverage for private psychological counselling, and a lack of eating disorder education. Main facilitators were, having a knowledgeable family physician, psychological support, the outpatient program, the eating disorder advocacy organization, parent support groups, and the adolescent eating disorder service. At times, barriers and facilitator were paradoxical such as the family physician who could help the patient receive quick specialized eating disorder care, or who might not refer the patient on to more specialized services until they were quite ill and required drastic medical help.

The most important recommendations focus on increasing the number of experienced clinical psychologists in the province, providing family physicians with more education about eating disorders, changing hospital policy, increasing the scope of public health insurance coverage, improving some staffing concerns such as specific training for treating eating disorders, and increasing resources for various organizations. Some ideas for system

reorganization included having more psychologists specializing in eating disorder care, having more appropriate food being offered to youth in hospital being treated for an eating disorder, having more training for staff in caring for these youth, and for staff to provide parents with specific guidance that would be helpful for their situation. Participants also spoke of the need for individuals to be motivated to change, the benefits of parental advocacy, and the helpful services offered from the eating disorder advocacy organization.

These findings provide insight into the provincial health system where improvements can be made to address barriers to care. They also highlight youth stories of recovery: what has helped them, and where care in the health system should be praised. These unique journeys provide a snapshot of the experiences occurring in Atlantic Canada for youth who are trying to access health services. This study is a part of a larger project exploring access and care in the child and youth mental health system across Atlantic Canada and as such will have implications for the direction and recommendations for that project. As this type of study is fairly novel for the Atlantic Canadian population, there are plenty of avenues for further research in this field. The study findings may provide more insight and ideas for the Provincial Government Eating Disorder Roundtable or for the research exchange group to build on. This being said, it is important that current programs and services are continuously assessed to ensure that best practices are in place, in accordance with new literature, and in correspondence with the population needs. From a theoretical standpoint there is much to learn from a study of this nature in looking at access from youth and parent perspectives. Perhaps, this study will help guide how future similar projects will be designed, and may elicit some considerations that might not otherwise have been made.

The lessons learned from this study will contribute to the scholarship related to the area of eating disorder and mental health research. I believe this thesis will contribute to the current knowledge surrounding eating disorder care and services in Atlantic Canada. I think this thesis will also help in recognizing where improvements can occur, and what these improvements may look like.

By exploring both youth and parent voices, I hope that this study adds to our understanding of the differences in how stories are perceived, and in how a single journey can be interpreted from multiple perspectives, specifically within the same family context. It is essential that studies of a similar context occur in the future in order to understand how young people are experiencing care, and how this can be improved.

Furthermore, it is important to build upon these unique findings in exploring the similarities and differences in the multi-perspectives of youth and parents. I believe that engaging youth and their families in research provides for invaluable stories and insights into how systems are working and how systems are failing. This approach of collecting stories from two perspectives will continue to provide essential feedback for health researchers and policy makers. Engaging patients in research respects their voice, and as we have found in the current study, many people are enthusiastic to share their experiences to improve services for others:

I think what we went through worked, and I respect this kind of effort [the current study] to know to find out what's working, and what isn't, and to make recommendations, and to get information out there. So that's why I wanted to be here, and she did too [*Laura*], she jumped on the opportunity. (*Yvonne*).

Additionally, the thesis adheres with research values such as those shared by the MHCC (2009),

No single approach to the development of new knowledge can be used in all circumstances – a diversity of approaches must be nurtured and appropriately supported, and multiple sources of knowledge must be used. The primary objective must be to advance and deploy the best knowledge and evidence so that people living with mental health problems and illnesses and their families have timely access to appropriate and effective programs, services, treatments, and supports and that all people living in Canada have the opportunity to achieve the best possible mental health and well-being. (p. 78).

Furthermore, many participants have vocalized a similar disposition regarding the development of accessible mental health services:

I think it's as important to know what we do right, as it is to understand where the problems are, and to encourage and support and finance the things that are working right is a really important piece. (*Hilda*).

In closing, through the recommendations made by the participants in this thesis project and along with continued efforts to examine how services are delivered and can be reorganized, my desire is that there will be increased accessibility to appropriate eating disorder and mental health services. This will hopefully help to change the youth dialogue from stories of struggle to stories of triumph such as those shared by courageous young people like *Amir* in this project, “I would say I had anorexia; I wouldn't say I still do, which is wonderful.”

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Appendix A-Child Assent



Child/Youth Assent to Take Part in Research

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: <http://access-mentalhealth.ca/>

INVESTIGATOR (S):**Principal Investigator – Memorial University**

Dr. Rick Audas

Principal Investigators

Dr. Kate Tilleczek, University of Prince Edward Island

Dr. Scott Ronis, University of New Brunswick

Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow

Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you and your parent to decide whether you will be in the study or not. You can decide not to take part in the study. If you do take part, you are free to leave at any time. If any questions make you feel uncomfortable, you are free not to answer them.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This assent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

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Subject's Initials:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

1. Introduction/Background:

Child and youth mental health is a growing concern in Canada. The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. Purpose of study:

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. Description of the study procedures:

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. Length of time:

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a 'journey map.' This will involve placing items representing people, places, and things on a blank board to help show what your journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Assent Form.

5. Possible risks and discomforts:

We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counselling services will be made available to participants who require them.

6. Benefits:

You will receive \$30 as a thank you for your time. You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your experiences in the mental health care system.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Assent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. Liability statement:

Signing this form gives us your assent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

When you sign this assent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you only by a number or a code name in the final transcript.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for 15 years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tilleczek is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about you.

Exceptions to Confidentiality

Due to legal and ethical requirements, the research team must break confidentiality if:

- 1) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NL/NB, 18 in PEI, or 16 in NS;
- 2) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
- 3) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.

Principal Investigator's Name and Phone Number

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Subject's Initials:

Dr. Rick Audas
709-777-8867

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Board (NL)	(709) 777-6974, info@hrea.ca

10. Declaration of financial interest:

The members of the research team have no conflicts of interest to declare.

After signing this assent form you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:

- 1) *I have read and understood this assent form.*
- 2) *The study has been explained to me. All my questions were answered.*
- 3) *The possible harms and discomforts of this study have been explained to me.*
- 4) *I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.*
- 5) *I can ask any questions about the study at any time now and in the future.*
- 6) *I have been told that all research information will be kept confidential, except where required by law (e.g. suspected child abuse, court subpoena).*
- 7) *I understand that no information that would identify me will be released or printed.*
- 8) *I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.*
- 9) *I understand that I can keep a copy of the signed and dated Assent Form.*

To be filled out and signed by the participant:

	YES	NO
I agree, or give assent, to participate in an interview		
I agree, or give assent, to be contacted to participate in a second interview in about 2 years' time		
If yes, please provide contact details (email or phone): _____		
I agree, or give assent, to being audio-recorded as part of this study		
I agree, or give assent, to have my selected images photographed as part of this study		
I agree, or give assent, to have my 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ (understanding that I will not be identified in any way)		
In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic		
I agree, or give assent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give assent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)		

Signature of participant_____
Name printed_____
Year Month Day**To be signed by the investigator or person obtaining assent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the individual fully understands what is involved in their participation in the study, any potential risks of the study, and that he or she has freely chosen to assent to be in the study.

Signature of investigator_____
Name printed_____
Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ___ Yes ___ No

Please indicate how you would like to receive the summary:

Mail to home _____ Email to you _____

Other _____

Please provide a mailing or email address:

Name: _____

Organization (if applicable): _____

Street Address: _____

City: _____ Province: _____ Postal Code: _____

Email: _____



Appendix B-Child Face Sheet

ACCESS-MH Patient Journeys - Child/Youth Face Sheet

Please note: If any of these questions make you uncomfortable, you are free not to answer them.



Part 1 – ABOUT YOU

What is the name of the city or town where you live? _____

What is your age? _____

How do you identify your gender? _____

Were you born in Canada?

___ yes

___ no If no, in which country were you born? _____

In what year did you first come to Canada? _____

What language(s) do you most often speak at home? (check all that apply)

___ English

___ French

___ Other(s): _____

People in Canada come from many racial or cultural groups. You may belong to one or more groups on the following list.

Are you

___ Aboriginal (e.g. North American Indian, Métis, Inuit) ___ Arab

___ Black ___ Chinese

___ Japanese ___ Filipino

___ South Asian (e.g. East Indian, Sri Lankan, etc.) ___ White

___ Southeast Asian (e.g. Vietnamese, Cambodian, etc.) ___ Korean

___ West Asian (e.g. Iranian, Afghan, etc.) ___ Latin American

___ or another group; Please specify: _____

___ Declined

With whom do you currently live in your MAIN home? Please indicate the number of each.



___ mother ___ female guardian ___ foster mother ___ step-mother
 ___ father ___ male guardian ___ foster father ___ step-father
 ___ sister ___ half-sister ___ foster sister ___ sister (blended family)
 ___ brother ___ half-brother ___ foster brother ___ brother (blended family)
 ___ other (please specify): _____

Do you have another home you live in? ___ yes ___ no

If yes, who lives with you in that home? Please indicate the number of each.

___ mother ___ female guardian ___ foster mother ___ step-mother
 ___ father ___ male guardian ___ foster father ___ step-father
 ___ sister ___ half-sister ___ foster sister ___ sister (blended family)
 ___ brother ___ half-brother ___ foster brother ___ brother (blended family)
 ___ other (please specify): _____

Compared to other young people, do you feel that your family:

___ does not have enough money
 ___ has enough money
 ___ has lots of money
 ___ declined

Part 2 – ABOUT YOUR EDUCATION AND WORK

Are you in school now? ___ yes ___ no

If yes, what grade? _____

what school? _____

what are your favourite classes? _____

what classes do you find most difficult? _____

If no, what is the name of the last school you attended? _____

What is the highest Grade you completed? _____

Do you have a job? ___ yes ___ no If yes, how many hours do you work each week? _____

Part 3 – ABOUT MENTAL HEALTH



Do you know if you have received a formal diagnosis from a health professional (e.g., psychiatrist, psychologist) for a mental health condition? ____ Yes ____ No

If 'yes', what diagnosis(-es) did you receive and when did you receive them? (check as many as apply)

Diagnosis	Date Received (month/year)	To what extent does this mental health condition create problems for you in everyday life?				
		<i>Not at All</i>	<i>Little</i>	<i>Some-what</i>	<i>Much</i>	<i>A Great Deal</i>
__ Anxiety						
__ Depression						
__ Autism spectrum disorder						
__ Conduct disorder						
__ Eating disorder						
__ Other (please specify): _____						

If 'no', do you currently SELF-IDENTIFY as having any of the following mental health conditions? And since when do you feel you've had the condition? (check as many as apply)

Condition	Since (month/year)	To what extent does this mental health condition create problems for you in everyday life?				
		<i>Not at All</i>	<i>Little</i>	<i>Some-what</i>	<i>Much</i>	<i>A Great Deal</i>
__ Anxiety						
__ Depression						
__ Autism spectrum disorder						
__ Conduct disorder						
__ Eating disorder						
__ Other (please specify): _____						



THANK YOU FOR COMPLETING THIS FORM



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Appendix C-Child Poster



HAS YOUR LIFE BEEN TOUCHED BY MENTAL HEALTH CHALLENGES?

ARE YOU BETWEEN 10 AND 18 YEARS OLD?

DO YOU WANT TO TELL YOUR STORY?

CALL OR SEND AN EMAIL TO:

Cathy Peyton
709-777-8868 or cpeyton@mun.ca

You will be given \$30 to thank you for taking the time to participate in our research project. We are gathering stories from young people in PEI, NB, NS, and NL who are making journeys through the mental health system. People don't often have the chance to hear from children and youth on this topic.

For more information on the project, contact Dr. Kate Tilleczek (902-620-5127 or ktilleczek@upei.ca).

The Research Ethics Boards of UPEI, UNB, UPEI, and MUN have approved this research project. You may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca





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[INSERT TEAR-OFF STRIPS WITH CONTACT NAME/PHONE/EMAIL FOR
PRINTED POSTERS]



Appendix D-Child Protocol

Child/Youth Patient Journeys Interview – Time I

Note: Use developmentally appropriate language and a conversational approach; focus on narrative.

Questions and Probes:

A) Early signs (retrospective)

- Could you describe what was happening in your life when you first felt you would need support for your mental health? (family, school, friends, community, spiritual, other)
- What happened next? (probe with each of family, school, friends, community, spiritual,
- Were you pleased about this action or response? Why/why not?
- Start a journey map, what would be main elements of life journey at this time?
- What worked/did not work well for you? (at all levels- ACCESS and CARE)
- What would you have liked to have seen happen? (at all levels)
 - What would you do differently?

B) Entering the system (or not)

- After this initial phase, what happened when you were looking for support for your mental health? (family, school, friends, community, spiritual, other)
- What happened next? How much time did you wait? What did you do? What did other people (parents, friends, teachers, etc.) do?
- Were you pleased about this action or response? Why/why not?
- Return to the journey map, what would be the main elements of your life journey now?
- What worked/did not work well for you? (All levels, ACCESS and CARE)
- What would you have liked to have seen happen?
- What part did school, teachers, mental health, allied professionals, community supports, others play in this journey? How and what happened?

C) Exits and Returns

- Were there any times in which you left the system? Why? What happened?
- Did you return? Why, how, what happened?



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D) Recommendations and Directions (prospective)

- If you could speak to family doctors (therapists, teachers, parents, other kids, others) what would you like them to know about your journey?
- If you could make three recommendations for fixing the youth mental health system, what would they be?
- If you had a chance to map a system of youth mental health care in your province, what would it look like? Where would the young people and families begin and end in a perfect journey? Where are they mainly beginning and ending at present? (ACCESS and CARE)

Appendix E-Parent Consent



Parent Consent to Take Part in Research

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: <http://access-mentalhealth.ca/>

INVESTIGATOR(S):

Principal Investigator – Memorial University

Dr. Rick Audas

Principal Investigators

Dr. Kate Tilleczek, University of Prince Edward Island

Dr. Scott Ronis, University of New Brunswick

Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow

Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you do take part, you are free to leave at any time. If any questions make you feel uncomfortable, you are free not to answer them.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

Version date: June 2014: Barriers and Facilitators in Access to Child/Youth Mental Health -201-

Subject's Initials:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

2. Introduction/Background:

Child and youth mental health is a growing concern in Canada. The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. Purpose of study:

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. Description of the study procedures:

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. Length of time:

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your child's journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your child's journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your/your child's experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a 'journey map.' This will involve placing items representing people, places, and things on a blank board to help show what your child's journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Consent Form.

5. Possible risks and discomforts:

We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counselling services will be made available to participants who require them.

6. Benefits:

You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your or your child's experiences in the mental health care system.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you only by a number or a code name in the final transcript.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for 15 years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tilleczek is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about you.

Exceptions to Confidentiality

Due to legal and ethical requirements, the research team must break confidentiality if:

- 4) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NB/NL, 18 in PEI, 16 in NS or;
- 5) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
- 6) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.

Principal Investigator's Name and Phone Number**Dr. Rick Audas****709-777-8867**

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Board (NL)	(709) 777-6974, info@hrea.ca

10. Declaration of financial interest:

The members of the research team have no conflicts of interest to declare.

After signing this consent you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:

- 1) *I have read and understood this consent form.*
- 2) *The study has been explained to me. All my questions were answered.*
- 3) *The possible harms and discomforts of this study have been explained to me.*
- 4) *I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.*
- 5) *I can ask any questions about the study at any time now and in the future.*
- 6) *I have been told that all research information will be kept confidential, except where required by law (e.g. suspected child abuse, court subpoena).*
- 7) *I understand that no information that would identify me will be released or printed.*
- 8) *I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.*
- 9) *I understand that I can keep a copy of the signed and dated Consent Form.*

To be filled out and signed by the participant:

	YES	NO
I agree, or give consent, to participate in an interview		
I agree, or give consent, to be contacted to participate in a second interview in about 2 years' time		
If yes, please provide contact details (email or phone): _____		
I agree, or give consent, to being audio-recorded as part of this study		
I agree, or give consent, to have my selected images photographed as part of this study		
I agree, or give consent, to have my 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ (understanding that I will not be identified in any way)		
In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic		
I agree, or give consent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give consent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)		

Signature of participant_____
Name printed_____
Year Month Day**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the individual fully understands what is involved in their participation in the study, any potential risks of the study, and that he or she has freely chosen to consent to be in the study.

Signature of investigator_____
Name printed_____
Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ____ Yes ____ No

Please indicate how you would like to receive the summary:

Mail to home ____ Email to you ____

Other _____

Please provide a mailing or email address:

Name: _____

Organization (if applicable): _____

Street Address: _____

City: _____ Province: _____ Postal Code: _____

Email: _____



Appendix F-Parent Face Sheet

ACCESS-MH Patient Journeys - Parent/Guardian Face Sheet

Please note: If any of these questions make you uncomfortable, you are free not to answer them.



Part 1 – ABOUT YOU

What is the name of the city or town where you live? _____

What is your age? ___ under 22 ___ 22-30 ___ 31-40 ___ 41-50 ___ 51-60 ___ 61+

How do you identify your gender? _____

Were you born in Canada?

___ yes

___ no If no, in which country were you born? _____

In what year did you first come to Canada? _____

What language(s) do you most often speak at home? (check all that apply)

___ English

___ French

___ Other(s): _____

People in Canada come from many racial or cultural groups. You may belong to one or more groups on the following list.

Are you

___ Aboriginal (e.g. North American Indian, Métis, Inuit) ___ Arab

___ Black ___ Chinese

___ Japanese ___ Filipino

___ South Asian (e.g. East Indian, Sri Lankan, etc.) ___ White

___ Southeast Asian (e.g. Vietnamese, Cambodian, etc.) ___ Korean

___ West Asian (e.g. Iranian, Afghan, etc.) ___ Latin American

___ or another group; Please specify: _____

___ Declined

Part 2 – ABOUT YOUR FAMILY AND HOUSEHOLD



What is your marital status?

- ☐ single ☐ married ☐ common-law relationship
☐ separated ☐ divorced ☐ widowed
☐ other. Please specify: _____

How many children do you have? _____

How old is/are your son(s)? _____ daughter(s)? _____

How often do your children live with you?

- ☐ full-time
☐ 50% of the time
☐ on weekend and holidays
☐ other amount. Please specify: _____
☐ do not live with me

Who is/are the individuals directly involved in the raising of your child(ren)? Check as many as apply. If parents are the same gender, check twice.

- ☐ mother ☐ female guardian ☐ foster mother ☐ step-mother
☐ father ☐ male guardian ☐ foster father ☐ step-father
☐ sister ☐ half-sister ☐ foster sister ☐ sister (blended family)
☐ brother ☐ half-brother ☐ foster brother ☐ brother (blended family)
☐ maternal grandmother ☐ maternal grandfather
☐ paternal grandmother ☐ paternal grandfather
☐ maternal aunt ☐ maternal uncle ☐ maternal cousins
☐ paternal aunt ☐ paternal uncle ☐ paternal cousins
☐ other. Please specify: _____

How many of your children have experienced mental health challenges? _____

Are any of your children participating in this study?

- ☐ yes; How many? _____
☐ no
☐ not sure

In which of the following categories does your household income fall?

- ☐ less than \$10,000
☐ \$10,000 to less than \$20,000



- ___ \$20,000 to less than \$30,000
 ___ \$30,000 to less than \$40,000
 ___ \$40,000 to less than \$50,000
 ___ \$50,000 to less than \$60,000
 ___ \$60,000 to less than \$70,000
 ___ \$70,000 to less than \$80,000
 ___ \$80,000 to less than \$90,000
 ___ \$90,000 to less than \$100,000
 ___ \$100,000 or more
 ___ no income
 ___ declined

Part 3 – ABOUT YOUR EDUCATION AND WORK

Do you currently have a job? ___ yes ___ no

If 'yes':

Where do you work? _____

Job title: _____

How long have you been in this position? _____

What are your current educational qualifications? (check as many as apply)

- ___ High School diploma
 ___ Trade School
 ___ College diploma/Some university education
 ___ Undergraduate university degree
 ___ Graduate degree (please specify degree/major): _____
 ___ Other graduate degree (please specify degree/major): _____
 ___ None of the above

Part 4 – ABOUT MENTAL HEALTH

Do you have a child (or have care of a child) with a formal diagnosis from a health professional (e.g., psychiatrist, psychologist) for a mental health condition? ___ Yes ___ No

If 'yes', what is/are your child's diagnosis(-es)? (check as many as apply)

Diagnosis	Date Received (month/year)	To what extent does this mental health condition create problems for your child in everyday life?



		<i>Not at All</i>	<i>Little</i>	<i>Some-what</i>	<i>Much</i>	<i>A Great Deal</i>
__Anxiety						
__Depression						
__Autism spectrum disorder						
__Conduct disorder						
__Eating disorder						
__Other (please specify): _____						

If 'no', do you have a child who currently SELF-IDENTIFIES as having any of the following mental health conditions? And since when has your child self-identified with the condition?
(check as many as apply)

Condition	Since (month/year)	To what extent does this mental health condition create problems for your child in everyday life?				
		<i>Not at All</i>	<i>Little</i>	<i>Some-what</i>	<i>Much</i>	<i>A Great Deal</i>
__Anxiety						
__Depression						
__Autism spectrum disorder						
__Conduct disorder						
__Eating disorder						
__Other (please specify): _____						

Have you paid for any care services for your child's mental health? __ yes __ no

If yes, approximately how much have you paid in total? _____

Would you be willing to pay for:

faster services? __ yes __ no

Why or Why Not?



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If yes, how much? _____

better services? __ yes __ no

Why or Why Not?

If yes, how much? _____



THANK YOU FOR COMPLETING THIS FORM



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UNIVERSITY OF
NEW BRUNSWICK



UNIVERSITÉ DE MONCTON
EDMUNDSTON MONCTON SHIPPAGAN



SAINT MARY'S
UNIVERSITY SINCE 1802

One University. One World. Yours.

Appendix G-Parent Poster



HAS YOUR CHILD'S LIFE BEEN TOUCHED BY MENTAL HEALTH CHALLENGES?

**DO YOU HAVE A CHILD BETWEEN 5 AND 18 YEARS OLD WHO IS EXPERIENCING:
ANXIETY, DEPRESSION, AUTISM SPECTRUM DISORDERS, CONDUCT DISORDER,
OR EATING DISORDERS?**

DO YOU WANT TO TELL YOUR STORY?

CALL OR SEND AN EMAIL TO:

Cathy Peyton
709-777-8868 or cpeyton@mun.ca

We are gathering stories from parents/guardians in PEI, NB, NS, and NL whose children are making journeys through the mental health system. People don't often have the chance to hear from parents and guardians on this topic.

For more information on the project, contact Dr. Kate Tilleczek (902-620-5127 or ktilleczek@upei.ca).

The Research Ethics Boards of UPEI, UNB, UPEI, and MUN have approved this research project. You may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca





Appendix H-Parent Protocol

Parent Patient Journeys Interview – Time I

Note: Use developmentally appropriate language and a conversational approach; focus on narrative.

Questions and Probes:

A) Early signs (retrospective)

- Could you describe what was happening in your child's life when you first felt they would need support for their mental health? (family, school, friends, community, spiritual, other)
- What happened next? (probe with each of family, school, friends, community, spiritual, etc.)
- Were you pleased about this action or response? Why/why not?
- Start a journey map, what would be main elements of life journey at this time?
- What worked/did not work well for your child? (at all levels- ACCESS and CARE)
- What would you have liked to have seen happen? (at all levels)
 - What kind of support do you wish had been available in the beginning? (e.g., more information on support services or wait times, financial support, people to talk to, etc.)
 - What would you do differently?

B) Entering the system (or not)

- After this initial phase, what happened when you and your child were looking for support for their mental health? (family, school, friends, community, spiritual, other)
- What happened next? How long did you wait? What did you do?
- Were you pleased about this action or response? Why/why not?
- Return to the journey map, what would be the main elements of your life journey now?
- What worked/did not work well for you? (All levels, ACCESS and CARE)
- What would you have liked to have seen happen?
- What part did school, teachers, mental health, allied professionals, community supports, others play in this journey? How and what happened?



- What care services were available to you? How were those services coordinated? Was there any repetition in what was offered (redundancy)? How do you think services could be improved?
 - Did you pay for any services? Are you willing to pay for a better or faster service? How much?

C) Exits and Returns

- Were there any times in which your child left the system? Why? What happened?
- Did your child return? Why, how, what happened?

D) Recommendations and Directions (prospective)

- If you could speak to family doctors (therapists, teachers, other parents, kids, others) what would you like them to know about your child's journey?
- If you could make three recommendations for fixing the youth mental health system, what would they be?
 - What services should be provided? Which services should be redesigned to work better for you?
- If you had a chance to map a system of youth mental health care in your province, what would it look like? Where would the young people and families begin and end in a perfect journey? Where are they mainly beginning and ending at present? (ACCESS and CARE)

Appendix I-Parent Consent for Child



Parent (for Child/Youth) Consent to Take Part in Research

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: <http://access-mentalhealth.ca/>

INVESTIGATOR(S):

Principal Investigator – Memorial University

Dr. Rick Audas

Principal Investigators

Dr. Kate Tilleczek, University of Prince Edward Island

Dr. Scott Ronis, University of New Brunswick

Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow

Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

Your child has been invited to take part in a research study. Taking part in this study is voluntary. It is up to you and your child to decide whether they will be in the study or not. You and your child can decide not to take part in the study. If your child does take part, your child is free to leave at any time. If any questions make your child feel uncomfortable, they are free not to answer them.

Before you and your child decide, you and your child need to understand what the study is for, what risks your child might take and what benefits your child might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

Version date: June 2014: Barriers and Facilitators in Access to Child/Youth Mental Health -216-

Subject's Initials:

The researchers will:

- discuss the study with you and your child
- answer your questions
- keep confidential any information which could identify your child personally
- be available during the study to deal with problems and answer questions

3. Introduction/Background:

Child and youth mental health is a growing concern in Canada. The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. Purpose of study:

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. Description of the study procedures:

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. Length of time:

If you choose to allow your child to participate in this research project it will take 90-120 minutes of their time. Your child will be asked to participate in an interview of 60-90 minutes to talk about their journey with mental health. Prior to the interview, your child will be asked to find 3-5 visual images that they feel represent their journey in some way and to bring these to the interview (this is not required, but can be a helpful way for children/youth to think and talk about their experiences). At the beginning of the interview, your child will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview your child will be asked to create a

‘journey map.’ This will involve your child placing items representing people, places, and things on a blank board to help show what their journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether your child can be contacted for this purpose on the attached Consent Form.

5. Possible risks and discomforts:

We know of no harm that taking part in this study could cause your child. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counselling services will be made available to participants who require them and extra care will be taken to explain to your child that participation is voluntary and that they may choose to stop participating at any time.

6. Benefits:

Your child will receive \$30 as a thank you for their time. You and your child may not benefit directly from this study. There is no guarantee that your child’s participation will directly lead to changes in mental health services or changes in your or your child’s experiences in the mental health care system.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. Liability statement:

Signing this form gives us your consent to allow your child to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your or your child’s legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my child’s privacy and confidentiality?

Protecting your child’s privacy is an important part of this study. Every effort to protect your child’s privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from your child

- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify your child only by a number or a code name in the final transcript.

Other people may need to look at the study records that identify your child by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

Your child's name and contact information will be kept secure by the research team. It will not be shared with others without your and your child's permission. Your child's name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for 15 years.

If you or your child decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tiliczek is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about your child.

Exceptions to Confidentiality

Due to legal and ethical requirements, the research team must break confidentiality if:

- 7) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NL/NB, 18 in PEI, or 16 in NS;
- 8) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
- 9) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.

Principal Investigator's Name and Phone Number

Dr. Rick Audas

709-777-8867

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your child's participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

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NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Board (NL)	(709) 777-6974, info@hrea.ca

10. Declaration of financial interest:

The members of the research team have no conflicts of interest to declare.

After signing this consent you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:

- 1) *I have read and understood this consent form.*
- 2) *The study has been explained to me. All my questions were answered.*
- 3) *The possible harms and discomforts of this study have been explained to me.*
- 4) *I understand that I have the right to refuse to allow my child to take part in this study. I also have the right to withdraw my child from this study at any time. e.g., before or even after the recordings are made.*
- 5) *I and my child can ask any questions about the study at any time now and in the future.*
- 6) *I have been told that all research information will be kept confidential, except where required by law (e.g., suspected child abuse, court subpoena).*
- 7) *I understand that no information that would identify my child will be released or printed.*
- 8) *I understand that no information about my child (including recordings) will be given to anyone or be published without first asking my and my child's permission.*
- 9) *I understand that I can keep a copy of the signed and dated Consent Form.*

To be filled out and signed by the participant:

	YES	NO
I agree, or give consent, for my child to participate in an interview		
I agree, or give consent, for my child to be contacted to participate in a second interview in about 2 years' time If yes, please provide contact details (email or phone): _____		
I agree, or give consent, to my child being audio-recorded as part of this study		
I agree, or give consent, to have my child's selected images photographed as part of this study		
I agree, or give consent, to have my child's 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ (understanding that my child will not be identified in any way)		
In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic		
I agree, or give consent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give consent, to allow the use of anonymous quotations from my child's interview in research reports (understanding that my child will not be identified in any way)		

Signature of parent/guardian_____
Name printed_____
Year Month Day_____
Name of Child**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the individual fully understands what is involved in their child's participation in the study, any potential risks of the study, and that he or she has freely chosen to consent to their child being in the study.

Signature of investigator_____
Name printed_____
Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ____ Yes ____ No

Please indicate how you would like to receive the summary:

Mail to home ____ Email to you ____

Other _____

Please provide a mailing or email address:

Name: _____

Organization (if applicable): _____

Street Address: _____

City: _____ Province: _____ Postal Code: _____

Email: _____

Appendix J-Youth Consent



Youth Consent to Take Part in Research (for those 18 years in NS/PE and those 19 years in NL/ NB)

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: <http://access-mentalhealth.ca/>

INVESTIGATOR(S):

Principal Investigator – Memorial University

Dr. Rick Audas

Principal Investigators

Dr. Kate Tilleczek, University of Prince Edward Island

Dr. Scott Ronis, University of New Brunswick

Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow

Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you do take part, you are free to leave at any time. If any questions make you feel uncomfortable, you are free not to answer them.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

4. Introduction/Background:

Child and youth mental health is a growing concern in Canada. The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. Purpose of study:

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. Description of the study procedures:

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. Length of time:

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a 'journey map.' This will involve placing items representing people,

places, and things on a blank board to help show what your journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Consent Form.

5. Possible risks and discomforts:

We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counselling services will be made available to participants who require them.

6. Benefits:

You will receive \$30 as a thank you for your time. You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your experiences in the mental health care system.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you only by a number or a code name in the final transcript.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for 15 years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tiliczek is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about you.

Exceptions to Confidentiality

Due to legal and ethical requirements, the research team must break confidentiality if:

- 10) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NL/NB, 18 in PEI, or 16 in NS;
- 11) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
- 12) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.

Principal Investigator's Name and Phone Number

Dr. Rick Audas

709-777-8867

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Board (NL)	(709) 777-6974, info@hrea.ca

10. Declaration of financial interest:

The members of the research team have no conflicts of interest to declare.

After signing this consent you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:

- 1) *I have read and understood this consent form.*
- 2) *The study has been explained to me. All my questions were answered.*
- 3) *The possible harms and discomforts of this study have been explained to me.*
- 4) *I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.*
- 5) *I can ask any questions about the study at any time now and in the future.*
- 6) *I have been told that all research information will be kept confidential, except where required by law (e.g., suspected child abuse, court subpoena).*
- 7) *I understand that no information that would identify me will be released or printed.*
- 8) *I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.*
- 9) *I understand that I can keep a copy of the signed and dated Consent Form.*

To be filled out and signed by the participant:

	YES	NO
I agree, or give consent, to participate in an interview		
I agree, or give consent, to be contacted to participate in a second interview in about 2 years' time		
If yes, please provide contact details (email or phone): _____		
I agree, or give consent, to being audio-recorded as part of this study		
I agree, or give consent, to have my selected images photographed as part of this study		
I agree, or give consent, to have my 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ (understanding that I will not be identified in any way)		
In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic		
I agree, or give consent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give consent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)		

Signature of participant_____
Name printed_____
Year Month Day**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the individual fully understands what is involved in their participation in the study, any potential risks of the study, and that he or she has freely chosen to consent to be in the study.

Signature of investigator_____
Name printed_____
Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ____ Yes ____ No

Please indicate how you would like to receive the summary:

Mail to home ____ Email to you ____

Other _____

Please provide a mailing or email address:

Name: _____

Organization (if applicable): _____

Street Address: _____

City: _____ Province: _____ Postal Code: _____

Email: _____



Appendix K-Recruitment Support Letter

Title of Research Project:

Barriers and Facilitators in Access to Child/Youth Mental Health Services

Project Website: <http://access-mentalhealth.ca/>

Principal Investigator – UPEI

Dr. Kate Tilleczek (902) 620-5127

Principal Investigators

Dr. Rick Audas, Memorial University of Newfoundland

Dr. Scott Ronis, University of New Brunswick

Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow

Dr. Brandi Bell, University of Prince Edward Island

Dear _____,

We are conducting research designed to develop a better understanding of the impact that mental health conditions have on children/youth, caregivers, service providers (e.g., health, education, social development), and society. We also aim to identify barriers to access and promising practices across the four Atlantic Canadian provinces (New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador). An Atlantic Advisory Board with members from each province is helping to guide the project. We will be speaking with children/youth, parents, and service providers in each province.

The goal of this project is to take a diverse and innovative approach to studying how services are provided to children and youth identified with any of the following five mental health conditions: anxiety, depression, autism spectrum disorders, conduct disorder, and eating disorders. We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers). To do so, we are using interviews augmented with a visual mapping process (i.e., participants will have an opportunity to create a 'picture' of a journey through mental health using materials provided). Information collected will be shared and compared across provinces.

We are asking your assistance in recruiting participants into this project. If you are interested in helping us with recruitment, please contact Cathy Peyton at cpeyton@mun.ca or 709-777-8868, to discuss the demographic we are looking for.

We will be sharing the results of this project with participants in short summaries over the course of the project. If you are interested in receiving these summaries and/or the final report of the study, we will be happy to share them with you. The sponsor/funder of this research is the Canadian Institutes of Health Research (CIHR).



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Thank you for considering our request.

Sincerely,

Dr. Rick Audas

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca

Appendix L-Resource Card

<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>	<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>
<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>	<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>
<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>	<p><u>ACCESS-MH: Resources</u></p> <p>Please call 911 in the case of an emergency.</p> <p>Kids Help Phone: 1-800-668-6868</p> <p>Website: kidshelpphone.ca</p> <p>Find More:</p> <p>www.kidshelpphone.ca/ResourcesAroundMe/</p> <p>Canadian Mental Health Association</p> <p>Toll Free: 1-877-753-8550</p> <p>Website: cmhanl.ca/</p> <p>Central Intake for Children and Youth</p> <p>Phone: (709) 777-2200</p> <p>Outreach, Promotion and Prevention Services</p> <p>Phone: (709) 777-5074</p>

Mental Health Services

Website: westernhealth.nl.ca/index.php/programs-and-services/service-a-z/mental-health

Thrive Directory of Services

Website: thrivecyn.ca/directory-of-services/health/

Crisis Line:

Toll-Free: 1-888-737-4668

HealthLine

Phone: 1-888-709-2929

Mind Your Mind:

Website: www.mindvourmind.ca

Mental Health Services

Website: westernhealth.nl.ca/index.php/programs-and-services/service-a-z/mental-health

Thrive Directory of Services

Website: thrivecyn.ca/directory-of-services/health/

Crisis Line:

Toll-Free: 1-888-737-4668

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Website: westernhealth.nl.ca/index.php/programs-and-services/service-a-z/mental-health

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Crisis Line:

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Mind Your Mind:

Website: www.mindvourmind.ca

Mental Health Services

Website: westernhealth.nl.ca/index.php/programs-and-services/service-a-z/mental-health

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Website: www.mindvourmind.ca

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Website: westernhealth.nl.ca/index.php/programs-and-services/service-a-z/mental-health

Thrive Directory of Services

Website: thrivecyn.ca/directory-of-services/health/

Crisis Line:

Toll-Free: 1-888-737-4668

HealthLine

Phone: 1-888-709-2929

Mind Your Mind:

Website: www.mindvourmind.ca



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Appendix M-Stakeholder Email Invite

Dear _____,

We are conducting research designed to develop a better understanding of the impact that mental health conditions have on children/youth, caregivers, service providers (e.g., health, education, social development), and society. We also aim to identify barriers to access and promising practices across the four Atlantic Canadian provinces (New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador). An Atlantic Advisory Board with members from each province is helping to guide the project. We will be speaking with children/youth, parents, and service providers in each province.

The goal of this project is to take a diverse and innovative approach to studying how services are provided to children and youth identified with any of the following five mental health conditions: anxiety, depression, autism spectrum disorders, conduct disorder, and eating disorders. We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers). To do so, we are using interviews augmented with a visual mapping process (i.e., participants will have an opportunity to create a 'picture' of a journey through mental health using materials provided). Information collected will be shared and compared across provinces.

As a service provider who works with children/youth with mental health conditions, we would like to invite you to participate in this project. Please see the attached Information Letter. If you are interested, please contact Cathy Peyton at cpeyton@mun.ca or 709-777-8868, to schedule an interview.

The sponsor/funder of this research is the Canadian Institutes of Health Research (CIHR).



Thank you for considering our request.

Sincerely,

Dr. Rick Audas

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located.

Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upe.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca



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Appendix N-Certificate of Volunteer Participation



Certificate of Volunteer Participation

Name: _____ Date: _____

Thank you for your volunteer participation in our research project *Barriers and Facilitators in Access to Child/Youth Mental Health Services*. Volunteers are the backbone of social science research; without you, we could not do our work.

We are sincerely grateful for the time you have dedicated to our project. You have willingly shared your experiences with us and helped us to ask informed questions of other young people in Atlantic Canada. We hope that the opportunity has been as valuable to you as it was to our research team.

You have been part of an important and ground-breaking research project. The information you have shared has provided valuable insight regarding the impact that mental health conditions have on children, caregivers, service providers (e.g., health, education, social development), and society. This information will help educators, government, and communities develop programs and policies to enhance the life experiences of young people.

Thank you again for your time and expertise. We trust that your future employers and educators will also see the value in your volunteer work with us. We will keep you informed about the work we are doing and invite you to visit our website to learn more at <http://access-mentalhealth.ca/>.

Sincerely,

Kate Tillecze, PhD

katetilleczek.ca

Professor and Canada Research Chair

Director, Young Lives Research – UPEI

Research Scientist (Adjunct)

Hospital for Sick Children, Toronto, Canada





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Appendix O-Interview Debriefing Script

ACCESS-MH Patient Journeys - Interview Debriefing Script

That is all the questions that I have for you. Do you have anything else you like to add or any questions for me?

Thank you very much for sharing your journey with me. It is very important to us that we hear from children, youth, parents and service providers to learn more about what it is like for children and youth to experience mental health challenges and the mental health system.

[consult completed consent form]

Before you leave, I am going to take photographs of the images you brought and of your journey map (according to consent). [take photos]. Would you like to take your images with you or should I keep them?

We know that talking about these things can be difficult. Here is a list of resources in case you'd like to talk to someone. [provide laminated card with list of resources tailored to province, including local CMHA information]

Thanks again for your time. Here is a Certificate of Volunteer Participation (for child/youth and parent participants) and some compensation for your time/funds to cover your costs. [provide certificate; have participant sign receipt and then provide cash]

We will send you information about the study at a later time according to what you put on your consent form. In the meantime, if you (or your parents) ever have any questions about the research, feel free to contact us using the information on the copy of the consent forms that you (and your parents) have.

Appendix P-Child Protection Sheet

A child is in need of protection where the child **is being or is at risk of being**

- Physically harmed by the action or lack of appropriate action by the parent
- Sexually abused or exploited by the child's parent
- Emotionally harmed by the parent's conduct and there are reasonable grounds to believe that the emotional harm suffered by the child, or that may be suffered by the child, results from the actions, failure to act or pattern of neglect on the part of the parent
- Physically harmed by a person and the parent does not protect the child
- Sexually abused by a person and the parent does not protect the child
- Emotionally harmed by a person and the parent does not protect the child

is

- in the custody of a parent who refuses to or fails to obtain or permit essential medical, psychiatric, surgical or remedial care or treatment to be given to the child when recommended by a qualified health practitioner
- abandoned
- living in a situation where there is violence or is living in a situation where there is a risk of violence
- living with a parent whose actions show a propensity to violence or who has allegedly killed or seriously injured another person

has

- no living parent and no adequate provision has been made
- no parent available to care for the child and the parent has not made adequate provisions
- no parent able or willing to care for the child
- been left without adequate supervision appropriate to the child's developmental level

is actually or apparently under the age of 12 years and has

- Allegedly killed or seriously injured another person or has caused serious damage to another person's property or
- On more than one occasion caused injury to another person or other living thing or threatened, either with or without weapons, to cause injury to another person or other living thing, either with the parent's encouragement or because the parent does not respond adequately to the situation

Duty to Report:

The Minister of Child, Youth and Family services, Hon. Sandy Collins, can be reached by phone at (709) 729-0173.

Please see the Child and Youth Care and Protection Act for more information:
http://www.assembly.nl.ca/Legislation/sr/statutes/c12-2.htm#10_

Where a person has information that a child is or may be in need of protective intervention, the person shall immediately report the information to a manager, social worker or a peace officer.

The Minister of Child, Youth and Family services, Hon. Sandy Collins, can be reached by phone at (709) 729-0173.

Appendix Q-Youth in Crisis Protocol

ACCESS-MH Patient Journeys - Youth in Crisis Protocol

Youth in general distress: if a participant is in general distress during or after the interview, ensure that they keep the card of services in their area and indicate to them particular numbers that may be relevant to their situation. Interviewers can encourage youth to seek out assistance.

Youth in immediate crisis (including suicidal ideation/self-harm): if a participant appears to be in crisis and the interviewer is concerned about leaving them alone, the participant should be asked if they have a family member or friend that should be called. If so, help the participant to make this call, and remain with them until someone arrives. The interviewer can also suggest that they call the Kids Help Phone (offer a phone, if needed). If the interviewer remains concerned about the youth and does not wish to leave them alone, the next option is to either call 9-1-1 and wait for help to arrive (then accompany the person to the hospital) or accompany the participant to the nearest hospital emergency room in another way and wait with the youth until professional help arrives. In all circumstances of distress, the local field coordinator should be immediately notified.

To Support Youth in Immediate Crisis

- (1) If they would like to talk to someone immediately, suggest they call the **Kids Help Phone** (1-800-668-6868). Help them make this call. Stay with them until the situation is resolved.
- (2) Ask if there is a **family member or friend** they would like to call. Help them make this call. Stay with them until someone arrives.
- (3) If neither of the previous options helped to resolve the issue, **call 9-1-1** and wait with them until help arrives. Accompany them to the nearest hospital.
- (4) **Inform your local field coordinator.**

Appendix R- Interview Checklist

ACCESS-MH Patient Journeys - Checklist

Prior to the interview

- Digital recorder (in full working order) [take 2 if available]
- Digital camera (in full working order)
- Extra batteries
- Receipt book
- Honoraria, child care & travel costs (if applicable and prearranged)
- Participant ID code (put on Face Sheet and say into recorder at beginning of interview) [get this from Brandi]
- Consent/Assent forms (x2 – one copy for us, one for participant)
- Face Sheets (x2 – one copy for participant to follow if needed, one to be filled in; both to be returned)
- Interview protocol
- Journey Mapping Kit
- Certificate of Volunteer Participation (if applicable – for child/youth & parent/guardian participants)
- List of Services (if applicable – for child/youth & parent/guardian participants)

After the interview

- According to the participant's consent form, take photographs of their images and journey map.
- For child/youth and parent/guardian participants: Enter the participant's name on the Certificate of Volunteer Participation and give document to participant.
- For child/youth and parent/guardian participants: Provide them with the List of Services.
- For child/youth participant: Provide honorarium and applicable travel or child care costs and have them sign the receipt book.
- For parent/guardian participant: Provide any applicable travel or child care costs and have them sign the receipt book.

Return to local field coordinator

- Digital recorder(s)
- Digital camera
- Journey Mapping Kit
- Signed consent form



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Extra consent forms

Completed Face Sheet

Extra Face Sheets

Receipts for honoraria, child care, and/or travel payment

Appendix S- Composite List of Themes

Composite Themes

1. Psychological Services
2. School
3. Family Physician
4. Internet
5. Individualized Care
6. Outpatient Program
7. Hospital
8. Waiting period
9. Emotion Focused Family Therapy
10. Coaches- Food Restriction
11. Pediatric Psychiatry Unit
12. Coordination/Communication
13. Parents support group and Educational group-Advocacy Organization
14. Art Therapy
15. “Practical Advice”/Specific help
16. Meal Plan
17. Coverage
18. Meal Support
19. Dietician
20. Social Worker
21. Adolescent eating disorder service Specialist
22. Eating disorder advocacy organization
23. “Compassion”/Ignorance
24. Transition
25. Staff at outpatient program
26. Guidance Counsellor
27. Music
28. Education-Eating Disorder, Mental Health
29. Depression
30. Recovery
31. Group Therapy
32. Writing
33. Awareness
34. “Bad” Providers
35. “Good” Providers
36. Burden of Guilt
37. Excessive Exercise
38. Willingness/motivation to get better
39. Multidisciplinary support

40. Support whole family
41. Clinic
42. Clinic/program timing
43. Stigma
44. “Words to avoid”—staff and family education
45. Parent advocate—psychiatry unit for meals, food, help, out of province residential treatment centre
46. Lack of resources/capacity
47. Turning points
48. Child tell parent- “ I’m anorexic”, self aware
49. Timing in program-summer
50. Other families support/help
51. Child help others
52. Ideal journey
53. Resource in recovery
54. Geographical
55. Bullying
56. Good student
57. Making friends through services
58. Drugs/alcohol